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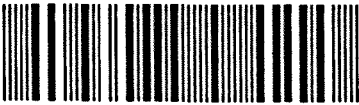
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**OXFORD REGIONAL TRAINING COURSE
IN CLINICAL PSYCHOLOGY**

Doctorate in Clinical Psychology

**An investigation into the relationship between
sleep problems and daytime behaviour difficulties
in adults with learning disabilities**

Gemma Gray

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definitive conclusions can be drawn. The efficacy of behavioural interventions was demonstrated, and the clinical and theoretical implications of the results were considered.

ABSTRACT

Sleep research with adults with learning disabilities has been limited. This study considered the sleep problems experienced by adults with learning disabilities in two main sections, a survey and an intervention. The survey assessed the prevalence, nature and range of sleep problems experienced by adults with learning disabilities who live at home with their families, and investigated the relationship between sleep problems and daytime behaviour disturbance. The intervention part of the study considered whether daytime behaviour difficulties reduced following a successful sleep intervention, and whether carer stress was influenced by an improvement in sleep problems.

Individuals with learning disabilities who live at home with their families had prevalence figures for sleep problems higher than those experienced by the general population. The relationship between sleep and behaviour problems was highly specific with settling problems predicting hyperactivity, lethargy, irritability and the overall score on behavioural measures. The interventions did not provide substantial evidence that sleep and behaviour were related, with only one of six participants demonstrating a decrease in behaviour problems following an improvement in sleep. Carer stress did not significantly reduce as a result of the intervention.

The study has provided prevalence rates of sleep problems for a population which has not been previously studied. It concludes that the relationship between sleep and behaviour

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CONTENTS

1.	<u>INTRODUCTION</u>	1
1.1	DEFINITIONS	2
1.2	SLEEP PROBLEMS IN CHILDREN WITH LEARNING DISABILITIES	3
1.2.1	Prevalence	3
1.2.2	Factors associated with sleep problems in children with learning disabilities	5
1.2.3	Professional involvement with sleep problems	6
1.2.4	Sleep problems as a form of challenging behaviour	7
1.3	SLEEP PROBLEMS IN ADULTS WITH LEARNING DISABILITIES	8
1.3.1	Current status of sleep research in adults with learning disabilities	8
1.3.2	Prevalence	8
1.3.3	Physiological Differences	9
1.3.4	Importance of sleep from a clinical perspective	10
1.4	THEORETICAL BASIS - SLEEP AND CHALLENGING BEHAVIOUR	11
1.4.1	Definition of challenging behaviour	11
1.4.2	Applied Behaviour Analysis	12
1.4.3	Sleep and the effect on behaviour	13
1.5	SLEEP INTERVENTIONS	16
1.5.1	Current status of sleep interventions	16
1.5.2	Behavioural Interventions	17
1.6	STRESS IN PARENTS OF PEOPLE WITH LEARNING DISABILITIES	18
1.7	METHODOLOGICAL ISSUES	19
1.7.1	Physiological Bias	20
1.7.2	Measures and assessment tools	21
1.7.3	Respondents	21

1.7.4	Behavioural Recording	22
1.8	SUMMARY	22
1.9	RESEARCH AIMS AND HYPOTHESES	24
1.9.1	Aims	24
1.9.2	Hypotheses	26
2.	<u>METHOD</u>	28
2.1	SURVEY	28
2.1.1	Participants	28
2.1.2	Design	28
2.1.3	Measures	28
2.1.4	Procedure	31
2.2	INTERVENTION	32
2.2.1	Participants	32
2.2.2	Design	34
2.2.3	Measures	35
2.2.4	Procedure	38
2.2.5	Intervention	40
3.	<u>RESULTS</u>	44
3.1	SURVEY - DEMOGRAPHIC INFORMATION	44
3.1.1	Response Rate	44
3.1.2	Sample characteristics	44
3.2	SURVEY - HYPOTHESES 1 AND 2	46
3.2.1	Prevalence of sleep problems	46
3.2.2	Influence of sleep on behaviour problems	53
3.3	INTERVENTION - DEMOGRAPHIC INFORMATION	57
3.4	INTERVENTION - HYPOTHESES 3 AND 4	60
3.4.1	Do improvements in sleep result in improvements in daytime challenging behaviour?	61

3.4.2	Impact of sleep intervention on carer stress	71
4.0	<u>DISCUSSION</u>	73
4.1	SUMMARY OF RESEARCH FINDINGS	73
4.1.1	Prevalence of sleep problems	73
4.1.2	Relationship between sleep problems and daytime behaviour disturbance	74
4.1.3	Carer stress and sleep problems	75
4.2	METHODOLOGICAL ISSUES	75
4.2.1	Response Rate	75
4.2.2	Sampling bias	77
4.2.3	Recordings of sleep and daytime behaviour	77
4.2.4	Measures of stress	78
4.3	THEORETICAL CONTEXT	78
4.4	CLINICAL IMPLICATIONS	80
4.4.1	Prevalence rates	80
4.4.2	Relationship between sleep and behaviour	82
4.4.3	Behavioural interventions	85
4.5	FUTURE RESEARCH	87
4.5.1	Prevalence	87
4.5.2	Relationship between sleep and behaviour	88
4.5.3	Carer stress and sleep problems	89
4.5.4	Behavioural interventions	90
4.6	CONCLUSIONS	91
	REFERENCES	93
	APPENDICES	

1. INTRODUCTION

Sleep is an activity in which most humans will spend approximately one third of their lifetime (Tyron, 1996). The topic of sleep has been well researched in general adult populations. However, there are many other populations who experience difficulties with their sleep that have been less well researched. This research focuses on sleep problems in those who have a learning disability, who are aged 18 years old or over, and who live at home with their parents. Firstly, it will investigate the prevalence and nature of sleep problems experienced by these individuals, and evaluate whether sleep disturbance affects daytime behaviour. Secondly, it will assess whether improvements in sleep result in changes in an individual's behaviour and in their carers' levels of stress. There are many forms of night time behaviour that are described under the term 'sleep problem' (Ferber, 1985; Guilleminault, 1987; Hauri, 1985; Sheldon, Spire & Levy, 1992). This study focuses on those who have problems settling to sleep and / or problems with waking during the night.

The introduction will begin by discussing definitions of sleep problems. It will review the literature regarding sleep problems in children with learning disabilities, followed by a review of what is known about sleep in adults with learning disabilities. It will continue by describing the theoretical context for the current study. It will then evaluate the empirical literature with regard to sleep interventions for children and adults with learning disabilities, and examine the impact of caring for a son / daughter with a learning disability

and a sleep problem. The conclusion will highlight methodological issues in previous research, and outline the research questions and hypotheses that have been generated for the current study.

1.1 DEFINITIONS

There is great diversity amongst definitions of sleep problems. The definitions in this study will draw upon those used for children both with and without learning disabilities. This is because, in the few studies that have been completed with adults, either child definitions have been used, or definitions have been completely omitted with results being based upon questions such as 'does X have a sleep problem?' Using the child literature definitions does not mean that people with learning disabilities should be perceived as children or childlike. It will simply make this piece of research more comparable with previous research in learning disabilities, both with adults and with children. In support of using such definitions is evidence that settling problems, night waking and short duration sleep are some of the most commonly experienced difficulties by people with learning disabilities (Stores, 1992b); the child literature provides clearly operationalised definitions for such difficulties.

The definitions used in this study were taken from Quine (1992) and from the Behavioural Screening Questionnaire (Richman & Graham, 1971). They are as follows:

Severe settling problem

- occurs three or more times per week;
- person takes more than an hour to settle and fall asleep;

Mild settling problem

- occurs once or twice per week;
- person settles in less than an hour;

Severe waking problem

- occurs three or more times per week;
- person wakes for more than a few minutes and disturbs the parents or goes into parents' bed or room;

Mild waking problem

- occurs once or twice per week.

Research evidence from both general populations and learning disabled populations provided the rationale for this study. To prevent confusion it can be taken that findings reported refer to those with learning disabilities unless otherwise stated.

1.2 SLEEP PROBLEMS IN CHILDREN WITH LEARNING DISABILITIES

1.2.1 Prevalence

Quine (1991; 1992) notes that sleep difficulties are common amongst children, including children who have a learning disability, with 65% and 87% of her sample of 76 children

with learning disabilities having settling and waking problems respectively. She notes,

sleep disturbance is one of the most widespread, persistent and stressful problems exhibited by young children with severe learning disabilities.

(Quine, 1992, pp. 299)

Clements, Wing & Dunn (1986) report a prevalence rate of 34% for sleep problems in their sample of 155 children with learning disabilities. Wiggs & Stores (1996) report that 44% (n=209) of children with learning disabilities had severe sleep problems (including early waking). Of those 209 children, 26% and 22% had settling and waking problems respectively. Eighteen per cent experienced difficulty with both. The duration of the sleep difficulties for the 44% with severe problems averaged 7.13 years. It has been suggested that children with learning disabilities 'grow out' of sleep problems at a slower rate than non-disabled children (Bartlett, Rooney & Spedding, 1985; Hewitt, 1985; Stores, 1992b). Quine (1993) notes that sleep problems persist and that children with learning disabilities followed up in her study three years later still had the same difficulties. Of those individuals who were aged 11-18 years old at three year follow up, 60% and 40% experienced waking and settling problems respectively. Clements et al. (1986) suggest that sleep problems in older children with learning disabilities have often existed since early childhood. This indicates that parents have experienced difficulties for many years.

1.2.2 Factors associated with sleep problems in children with learning disabilities

Sleep problems have been associated with particular syndromes. Quine (1992) reported that a child with a sleep problem was more likely to have cerebral palsy or another named condition, although not Down's Syndrome. Those with sleep difficulties were also more likely to have other behaviour problems than those who slept well. Zuckerman, Stevenson & Bailey (1987), in their study of non-learning disabled children, reported that behaviour difficulties were more likely to be present when the sleep problem persisted, i.e. was still present 2½ years later. Clements et al. (1986) report a similar association between sleep and behaviour problems in their study with children with learning disabilities, with children who awoke in the night more likely to show self-injurious behaviours, while those with settling difficulties more likely to be attached to their routines. Quine (1991) also shows that children with sleep problems were more likely to have daytime behaviour difficulties. If a child has a physical disability in addition to a learning disability there is greater likelihood of sleep disturbance, as the child may experience discomfort, spasms and other physical symptoms. (Burton, 1990; Stores, 1992a; Quine, 1993). This is likely to account for the high incidence of sleep problems in children with cerebral palsy. There is little research regarding the nature and extent of a relationship between sleep and daytime behaviour in children with learning disabilities, despite clinical impressions that improved sleep is likely to improve daytime behaviour. As Stores (1992b) notes:

There is a need to address the fundamental issue of the interplay between sleep disturbance and impairment of daytime performance and intellectual function.

(Stores, 1992b, pp.1314)

1.2.3 Professional involvement with sleep problems

Hunt & Stores (1994) report that, despite the impact that sleep problems have on families of children with learning disabilities, they are not offered much help from professionals. Quine's (1992) research supports this. In her sample of 76 children, of whom 65% and 87% had settling and waking problems respectively, only 7% of the children were receiving medication and only one was receiving help (behavioural intervention) from a clinical psychologist. The prevalence of sleep problems in children with learning disabilities is clearly concerning, yet it seems that parents are frequently left to cope with such difficulties on their own, despite some evidence from the general child and learning disability literature that behavioural interventions are effective and successful (Hewitt, 1985; Milan, Mitchell, Berger & Pierson, 1981; Richman, 1981; Sanders, Bor & Dadds, 1984). Quine (1993) describes proactive initiatives that help parents receive help with sleep problems. For example, providing information regarding available help, and providing regular assessments of the children.

Bartlett et al. (1985) reported a high incidence of severe sleep problems in children with learning disabilities (23%), but noted that 28 out of the 52 families with severe difficulties refused help. It is difficult to consider how these families could be helped. The same

authors asked those parents who did want help why they did not request help sooner.

Some parents had received sedatives for their child when they sought help and these did not work, hence they did not ask again. Other parents thought that they had other things 'to trouble professionals with', and some parents did not think it relevant to mention sleep problems because professionals rarely asked about the child's sleep. This highlights the need to educate professionals about the importance of routinely enquiring about sleep and about the availability of appropriate treatments.

1.2.4 Sleep problems as a form of challenging behaviour

It is interesting to note that despite the fact that sleep problems are common in children with learning disabilities and have adverse and far reaching consequences, they are rarely included in definitions of challenging behaviour (see Kiernan & Kiernan, 1994, for examples of challenging behaviours). Quine (1993) reasons that failure to categorise sleep difficulties as challenging behaviour is because it is an 'invisible' problem: it is not evident to service providers because it happens at night. It is possible that whilst children are in respite facilities their sleep may be disrupted, but this may not necessarily be considered problematic, particularly if the organisation has waking night staff who are there to cope with such events. Quine argues convincingly that sleep problems need to be recognised as a challenging behaviour.

1.3 SLEEP PROBLEMS IN ADULTS WITH LEARNING DISABILITIES

1.3.1 Current status of sleep research in adults with learning disabilities

Although limited, research on sleep in individuals with learning disabilities has tended to concentrate on children. Consequently, research on sleep in children with learning disabilities is more advanced than research with adults with learning disabilities. As Espie & Tweedie (1991) note, there has been little research regarding the nature / range of sleep problems in adults with learning disabilities. The same authors consider why there is this lack of research. They suggest that one primary reason is that individuals often do not complain of sleep problems because of inherent communication difficulties; thus the problems have not been given due consideration. Bartlett and colleagues (1985) also suggest that an individual's sleep is unlikely to be enquired about routinely, and that the existence of such problems may remain hidden. It is only usually when carers experience difficulties that help may be sought, even though satisfaction with sleep remains subjective and may be problematic for an individual prior to this. Brylewski (in press) argues that education for paid carers is necessary so that they can recognise and seek appropriate help for sleep disturbance.

1.3.2 Prevalence

Prevalence figures, definitions and methodologies vary between the small number of studies completed with adults. Some studies report overall percentages of sleep problems, whereas others report on the different types of problems that are experienced. Espie &

Tweedie (1991) conducted a study on 120 adults with learning disabilities. This sample was a combination of hospital and community residents, although it is unclear as to whether all of the 'community' residents lived with families or were in other residential provision with paid carers. They reported a prevalence rate of 15% for sleep problems. This is similar to prevalence figures quoted for the general population. However, these figures are based on carers answering yes / no as to whether or not they considered that a person had a sleep problem. This method is obviously problematic because, as Quine (1993) notes, there is often the assumption that sleep problems are part of a learning disability - significant problems may be experienced but not perceived as such by carers. Brylewski (in press), in a study of adults living in the community in supportive housing, reported 55% and 26% had night waking and settling difficulties respectively as indicated by paid carers. It is interesting to note that Espie, Paul, McFie & McColl (1995) report on another form of sleep difficulty, that is, people spending excessively long periods of time in bed. They suggest that this could be because sleep routines are arranged to suit the organisations rather than the individuals, and that putting people to bed early can be seen as a form of respite care or coping response from carers. It is likely that this will not be considered a problem by carers, which makes it difficult for professionals to offer help. No study has been conducted which only involves adults who live at home with their families.

1.3.3 Physiological Differences

Individuals with learning disabilities are already known to experience less rapid eye movement (REM) sleep than their equivalent counterparts without disabilities (Espie et al., 1995; Grubar, 1989). Benzodiazepines are frequently given to help people with

learning disabilities sleep. Yet there is evidence that these drugs are only effective in the short term (Espie, 1991; Morin & Wooten, 1996) and that they also suppress REM which is undesirable (Espie & Tweedie, 1991). Espie & Tweedie (1991) also note that REM sleep is necessary for information processing and that it contributes to an individual's ability to learn and organise information. People with learning disabilities who already have deficits in their ability to learn may experience greater difficulty if REM sleep is decreased further with medication. Thus, in addition to establishing the prevalence of sleep problems in this population, it would seem desirable to develop successful treatments that do not rely on medication. This is to ensure that individuals are not inappropriately prescribed medication that may only improve their sleep in the short term, and that is likely to have adverse effects on their ability to learn and function throughout the day (Espie et al., 1995).

1.3.4 Importance of sleep from a clinical perspective

Research has emphasised the importance of highlighting sleep as an issue to professionals working with adults with learning disabilities. Espie et al. (1995) view good sleep as vital to an individual's quality of life, noting that sleep is often seen as important in childhood, but can be lost as an issue when individuals move into adulthood. Stores (1992a; 1992c) comments on how sleep is often ignored when professionals take a history, and suggests better education is necessary for professionals currently being trained so that sleep is routinely addressed. The majority of the research with this population also asks carers about a person's sleep, with no studies asking clients themselves about their sleep, despite

there being suggestions that the subjective experience of sleep is important (Espie & Tweedie, 1991; Espie et al., 1995).

1.4 THEORETICAL BASIS - SLEEP AND CHALLENGING BEHAVIOUR

1.4.1 Definition of challenging behaviour

The term 'challenging behaviour' is widely used within the learning disabilities literature. As Qureshi (1994) notes, the term is used to highlight how services might respond to the behaviour that challenges achieving an ordinary life, rather than viewing the 'problems' as inherent within the individual. The same author comments on how the term has been used to emphasise a rather smaller group of individuals, rather than all those with behaviour difficulties, who may comprise 50 % of the learning disabled population. There have been attempts to delineate the differences between challenging behaviour and behaviour problems. Unfortunately, extensive coverage of this literature is beyond the scope of this study. For the purposes of this research challenging behaviour will be defined as:

Behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy; or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities.

(Emerson, Toogood, Barrett, Bell, Cummings & McCool, 1987)

This definition will be used in the broadest sense within this study because, as Qureshi (1994) notes, such a definition is subject to social processes, and depends upon how carers perceive particular behaviours. The term 'behaviour problems' will be used here interchangeably with the term 'challenging behaviour', as the participants in the current study rarely referred to behaviours as challenging, but preferred the term behaviour problems or difficulties.

It has been strongly argued (Quine, 1993) that sleep problems should be considered within definitions of challenging behaviour. As previously discussed, they are very common and persistent in children with learning disabilities, and are a source of stress to parents.

Although the research is limited, clinical impressions and preliminary findings suggest that the same is true for adults with learning disabilities. The wide ranging impact of sleep difficulties, both on individuals and on their carers, suggests that these difficulties adequately fulfil the definition of challenging behaviour as defined by Emerson et al. (1987), and should be seen as such, and not viewed simply as an ordinary developmental problem that will remit with age.

1.4.2 Applied Behaviour Analysis

It has been argued that the understanding of challenging behaviour in individuals with learning disabilities needs to include an ecological perspective, in which behaviour is seen as being influenced by the wider environment, rather than solely by immediate antecedents / consequences (Felce, 1991). Willems (1974) also encouraged behaviour analysts to

consider an ecological systems approach to applied problems. Consideration of ecological factors is an extension of applied behaviour analysis (Wahler & Fox, 1981) as it looks at, for example, the influence of a wide range of setting events on an individual's behaviour. That is, behaviour can be seen as being influenced by more "temporally distant" (Wahler & Fox, 1981, p.328) behaviour-environment interactions than was once thought. Hence events which are not necessarily observable and which may not occur immediately before a behaviour, e.g. hunger, pain, etc., may influence its occurrence. Within this theoretical context, sleep problems or sleep deprivation could be seen as a setting event for the occurrence of particular behaviours. This analysis could also be applied to carers in that, if they are deprived of sleep, sleep deprivation may influence their response to an individual which, in turn, might influence the individual's behaviours.

Support for extending the three term contingency (Antecedent-Behaviour-Consequence: A-B-C) model of analysing challenging behaviour to include setting events is extensive. Clements (1992) argues that an ABC model on its own does not include many other potential determinants of behaviour. O'Reilly (1995) suggests that functional analysis techniques need to include other variables that may be distant from the behaviour, but that may influence the probability of an individual responding in a particular way.

1.4.3 Sleep and the effect on behaviour

Consistent with an applied behaviour analytic perspective, Espie & Wilson (1993) note that there is a large amount of evidence from research with general populations to suggest

that a good sleep pattern has a positive impact on the health and functioning of individuals. The impact of inadequate sleep has been associated with impairments in daytime functioning, e.g. mood, arousal, task performance (Espie & Tweedie, 1991), tiredness, irritability, and anxiety (Stores, 1995) and could, therefore, be expected to contribute to difficult behaviour. However, this relationship has not been extensively investigated within the learning disabled population. Kiernan and Kiernan (1994) found that challenging behaviours during the day were more likely to be evident in those with learning disabilities who have reported sleep disturbance yet, as Minde, Faucon & Falkner (1994) noted, there is little data reporting on the effect of improved sleep on daytime behaviour. Wiggs & Stores (1996) demonstrated an association in children with learning disabilities between daytime behaviour and sleep problems. Those children with sleep problems were more likely to have higher scores on behavioural measures and show more irritability, lethargy, hyperactivity and stereotypic behaviours. Those with sleep problems had both more different types, and increased severity, of daytime challenging behaviours. However, this study acknowledges that such results do not permit conclusions with regard to the extent and role of sleep problems in challenging behaviour, because evidence of associations between variables does not indicate causal relationships. However, it concludes that sleep interventions may be effective in reducing challenging behaviour.

Other parts of an individual's environment have been studied in relation to challenging behaviour, e.g. levels of engagement and staff behaviour (Hastings & Remington, 1994a; 1994b), yet the influence of sleep on an individual's behaviour remains neglected, despite

suggestions that sleep problems influence daytime difficulties (Wiggs & Stores, 1996).

Espie (1992) emphasises the need for an 'optimal sleep wake schedule' so that an individual's learning potential can be maximised. He argues that sleep problems need to be viewed within a 24 hour perspective, and that functional analyses need to be applied across this period. Through this the relative influence of sleep problems on behaviour or vice-versa can be assessed.

Some single case studies with adults with learning disabilities (Espie, 1992; O'Reilly, 1995) have offered support for an association between sleep problems and challenging behaviour. O'Reilly reports on an individual who was aggressive to others whenever demands were placed on him (escape maintained aggression). This behaviour worsened when he was sleep deprived. An intervention (although not explicitly a sleep intervention) aimed at providing rest periods throughout the day resulted in a decrease in aggression. It would be interesting to speculate whether a sleep intervention aimed at ensuring this person was not sleep deprived would have had a similar effect on daytime behaviour. Espie (1992) also noted a decrease in behaviour problems and an increase in concentration when sleep improved. Unfortunately, general causality cannot be inferred from single cases, and Espie & Tweedie (1991) suggest that the next logical step in examining the relationship between sleep and behaviour would be to use a multiple baseline across subjects. Obviously there are many factors that are known to contribute to behaviour problems, so controlling for some of those known factors would be an important part of any investigation. Increased levels of impairment (Clements, 1992; Emerson, 1995;

Murphy, 1994), particular syndromes e.g. Lesch-Nyan (Emerson, 1995), epilepsy (Murphy, 1994), autism (Murphy, 1994), sensory impairments (Emerson, 1995), impaired mobility (Emerson, 1995) and greater impaired communication (Murphy, 1994) are all known to contribute to an increased likelihood of behavioural disturbance.

1.5 SLEEP INTERVENTIONS

1.5.1 Current status of sleep interventions

Clements et al. (1986) comment on the lack of interventions for sleep problems for children with learning disabilities in comparison to other behaviour problems that have been widely studied. They emphasise the urgent need to develop treatments so that family stress can be alleviated. It is noteworthy that the call for successful treatments was reported over a decade ago, yet there remains limited research on treatment evaluations with this population. More recent authors continue to highlight the need for extensive further research (e.g. Espie et al., 1995; Wiggs & Stores, 1996). In comparison to interventions for the general population, for which the literature is comprehensive (e.g. Espie, 1991; Espie & Lindsay, 1985; Espie, Lindsay & Brooks, 1988; Espie, Brooks & Lindsay, 1989; Horne, 1992; Lacks, 1987; Lacks, Bertelson, Sugarman & Kunkel, 1983), research into interventions for both children and adults with learning disabilities has lagged behind.

1.5.2 Behavioural Interventions

Some preliminary evidence demonstrates the success of behavioural treatments for sleep problems in children and adults with learning disabilities (Milan et al., 1981; Espie & Wilson, 1993). Quine (1993) describes a successful behavioural intervention with 26 children with learning disabilities. Techniques included positive routines, removal of reinforcers, extinction or graded leaving, and positive reinforcement. A cascade approach was used whereby other professionals were trained in behavioural treatments for sleep problems. A success rate of 80% was reported, with the improvements maintained for 21 of the children at three month follow-up. Parents were also more satisfied with their own sleep. Such studies demonstrate that a behavioural approach can be greatly beneficial to this population. In a study of adults with learning disabilities Hewitt (1985) showed improvement in eight out of nine adult subjects, with this improvement being maintained at follow up a year later for six of the original participants.

There is also evidence that sleep interventions with children without learning disabilities (aged one to three years) improve daytime behaviour as well as sleep (Minde et al., 1994). The authors do acknowledge, however, that there could be two possible reasons for this. Improvements in sleep could have a positive effect on the mood of the child and / or mother, or strategies learnt from sleep interventions could be transferred to other behaviours. Whatever the mechanism, the results are of great benefit clinically to clients.

Other sleep intervention studies using behavioural approaches with children (without learning disabilities) also show encouraging results, in terms of improvements in both sleep and daytime behaviour (Jones & Verduyn, 1983; Richman, Douglas, Hunt, Lansdown & Levere, 1985). However, little is known about behavioural (or any other) sleep interventions with adults with learning disabilities, and the impact that a successful intervention may have on daytime behaviour. Hunt & Stores (1994) suggest that intervention and longitudinal studies will help demonstrate whether improvements in sleep, in both children and adults with learning disabilities, will affect daytime behaviour.

1.6 STRESS IN PARENTS OF PEOPLE WITH LEARNING DISABILITIES

Caring for a person with a learning disability has been recognised as a stressful experience (Quine & Pahl, 1985). There are many factors that could contribute to this. However, sleep problems are reported as one of the most important factors known to contribute to family stress (Clements et al., 1986; Hunt & Stores, 1994; Quine, 1992; Quine & Pahl, 1985; Stores, 1992b). Quine notes:

Having a child with chronic sleep problems it seems, presents a considerable health risk for mothers which should not be ignored. (Quine, 1993, p.254)

In her study Quine (1993) reported an average score on the Malaise Inventory of 7.9 (SD = 3.4), for the mothers interviewed who had children with learning disabilities and

sleep problems. This indicates high levels of stress. Quine (1993) notes that the consequences of stress, such as tiredness and irritability, may also result in parents being unable to successfully carry out interventions that may alleviate sleep problems. This highlights the need for early identification and intervention for those with sleep problems, so that such high levels of stress can be prevented. What remains unclear however, is the extent to which improving an individual's sleep problems would result in a reduction of stress.

Carer stress is an important area to research, especially if the sleep problems are long-standing and remain from childhood. Stores (1992b) also notes that because sleep problems in the learning disabled population tend to persist beyond the age which they would tend to remit naturally, additional stress may be experienced. The existence of sleep problems and behaviour difficulties are both known to contribute to the stress experienced by parents. Given the increased likelihood of the co-existence of such problems, parents may be under 'double' the strain. Stress on families is likely to be great if problems are experienced throughout both the day and the night (Clements et al., 1986), especially if there is little or no remittance or respite from such difficulties.

1.7 METHODOLOGICAL ISSUES

One fundamental difficulty in assessing sleep is the great diversity in individual sleep patterns. As Clements et al. (1986) notes, there are few norms against which to compare

sleep patterns. The experience of sleep is subjective and what is considered adequate and satisfying for one person or their carers may not be for another. Espie & Wilson (1993) note that assessing the subjective aspect of sleep is difficult and can be unreliable. Inherent in any sleep study is the difficulty of obtaining accurate recordings of night time behaviour. By definition it occurs at a time when carers themselves are either asleep or trying to sleep, and accuracy of recording may be an important issue to consider for tired carers. For individuals with communication difficulties it is difficult for them to report information about their own sleep. It may be that they are awake during the night, but because they are quiet it is assumed by parents that they are asleep. Brylewski (in press) comments that paid carers often do not monitor clients' sleeping behaviour and it is therefore difficult to get an accurate account of nocturnal activities. In addition, she comments that even if a person complains about sleep, this is not always perceived to be important by carers, and carers may perhaps be unmotivated to seek help or keep records.

1.7.1 Physiological Bias

Within the general sleep literature there has been a research focus on the physiological aspects of sleep (Stores, 1992b), with particular attention paid to laboratory studies (Carskadon & Rechtschaffen, 1989). Despite there being developments to facilitate monitoring of variables at home (Broughton, 1989), the focus for those few studies with people with learning disabilities has remained on physiological components of sleep (Clausen, Sersen & Lidsky, 1977; Shibagaki, Kiyono & Matsuno, 1985).

1.7.2 Measures and assessment tools

There is also a great lack of relevant measures and assessment devices available for evaluating sleep (non-physiological aspects) in adults with learning disabilities. This is not surprising, given the lack of research in this area, but does mean that in the few studies that have been conducted measures developed for other populations tend to be used. This is problematic because it could be misleading to compare results from those individuals with learning disabilities with those from populations for whom the measure was devised. For example, it may be that such assessment tools assume that the type of sleep problems which the measure refers to are the same across the different populations. This may not be the case. Presumably, as interest in this area develops, the usefulness of these measures with regard to those with learning disabilities will be assessed and will, perhaps, stimulate more research into measures devised specifically for this population.

1.7.3 Respondents

Response rates in sleep studies vary greatly, with Wiggs & Stores (1996) reporting a response rate of 43% compared to the study by Brylewski (in press) of 85%. With smaller response rates it can be difficult to draw conclusions about particular populations. In surveys of sleep problems there is a potential for a bias in respondents, in that only those with sleep problems tend to reply (Wiggs & Stores, 1996), which may render the sample unrepresentative. In addition, Wiggs & Stores (1996) highlight the fact that questionnaires

may be subject to misinterpretation from carers, which means that results need to be considered with caution. This is particularly problematic because questionnaires rather than interviews are frequently the source of data for sleep studies.

1.7.4 Behavioural Recording

Inherent in investigating the relationship between sleep and behaviour is the necessity to obtain accurate recordings of both sleep and behaviour. Extensive work has been completed to establish accurate recordings of behaviour from carers. Unfortunately, in the absence of full time researchers who can shadow individuals, the method still relies upon simple behaviour diaries. This can be methodologically problematic. Firstly, it is difficult to ensure that all carers define and recognise particular behaviours similarly. Secondly, there can be a tendency not to record behaviours as they occur, perhaps waiting until the end of the day, hence making them vulnerable to memory distortions. Thirdly, there is some evidence to suggest that such diaries do not provide an accurate account of a client's activities, when compared to videos made at the same time (Joyce, Mansell & Gray, 1989).

1.8 SUMMARY

Very little is known about the sleep problems that may be experienced by adults with learning disabilities, particularly in comparison to what is known about sleep in children with learning disabilities. There is some evidence that the sleep problems experienced in

childhood continue into adulthood and are, therefore, likely to be persistent and long-standing. Brylewski (in press) reports prevalence figures for those individuals who live in residential services, but little is known about adults who live at home with their parents or carers. It is therefore important that epidemiological information is available regarding the nature and range of sleep problems for this population. Such information would be particularly useful in terms of service provision, so that services can adequately respond to those individuals and families who are experiencing sleep problems. Individuals who live at home have not been studied separately before, and such a study would be complementary to that completed on those living within supportive housing.

The understanding of challenging behaviour from an applied behaviour analysis perspective has developed in recent years. Professionals are now considering factors that are temporally distant from the behaviour, including setting events such as pain and hunger. Several authors have argued that these events may have an influence on particular behaviours. To date, sleep problems have not been widely considered as a possible contributory factor to difficult behaviour. However, it is argued here that they can be considered as setting events and, as such, have an influence on behaviour in adults with learning disabilities. The effects of sleep deprivation are well known, and provide some evidence that sleep problems are a potential factor in the existence of behaviour problems. However, before sleep problems can be regarded as a definite setting event for challenging behaviour in adults with learning disabilities, it is necessary to see whether sleep problems are better predictors of daytime behaviour difficulties than other factors associated with

behaviour problems. There is some preliminary evidence within the child and adult learning disability literature, suggesting that sleep difficulties can contribute to daytime behaviour problems and that, when sleep improves, then so does daytime functioning, although this has not been widely researched. The general child literature also provides some support that improvements in sleep using sleep interventions can result in an improvement in daytime behaviour. To the author's knowledge such a systematic study has not yet been conducted with adults with learning disabilities.

Caring for a son / daughter with a learning disability has been acknowledged to be a stressful task for parents. The presence of sleep problems has been identified as a major factor in the stress that is experienced. What remains unknown is the extent to which carers of adults with learning disabilities who have sleep problems experience similar levels of stress to those parents of children with sleep problems, and whether or not this is alleviated or decreased following a successful sleep intervention. Given that sleep problems are associated with carer stress, intervention studies are needed, with the aim of reducing carer stress as well as improving an individual's quality of life.

1.9 RESEARCH AIMS AND HYPOTHESES

1.9.1 Aims

The following aims were derived:

Aim 1

To assess the prevalence, nature and range of sleep problems in adults with learning disabilities who live at home with their families, including the duration of the problem and any professional help that has been received.

Aim 2

To investigate the relationship between sleep problems and daytime behavioural disturbance in adults with learning disabilities. There are many factors known to contribute to behaviour difficulties such as:

- increased levels of impairment (Murphy, 1994; Clements, 1992; Emerson, 1995);
- particular syndromes, e.g. Lesch-Nyan, Prader-Willi (Murphy, 1994; Emerson, 1995);
- epilepsy (Murphy, 1994);
- autism (Murphy, 1994);
- other sensory impairments (Emerson, 1995);
- impaired mobility (Emerson, 1995);
- restricted environment (Emerson, 1995);
- greater impaired communication (Murphy, 1994).

This study will evaluate whether there is a stronger relationship between sleep problems and behaviour disturbance, than between some of these variables and behaviour difficulties.

Aim 3

To investigate whether an intervention aimed at improving sleep problems will result in an improvement in daytime challenging behaviour (for a small group of clients).

Aim 4

To investigate the relationship between the stress experienced by carers of adults with learning disabilities and the existence of sleep problems. In particular, the study aims to evaluate whether carer stress is influenced by an improvement in sleep problems.

1.9.2 Hypotheses

From the research aims, the following hypotheses were generated:

Hypothesis 1

It was predicted that prevalence rates of sleep problems in adults with learning disabilities living at home with their families would be similar to those reported in adults with learning disabilities living in residential services.

Hypothesis 2

It was predicted that there would be a stronger relationship between sleep problems and daytime behaviour problems in adults with learning disabilities who live at home, than between a number of other possible variables and behavioural disturbance.

Hypothesis 3

It was predicted that a successful sleep intervention for adults with learning disabilities

would result in a subsequent improvement in daytime challenging behaviour (for a small group of clients)

Hypothesis 4

It was predicted that carer stress would reduce as a result of alleviating sleep difficulties.

2. METHOD

The current study had two main parts; a survey of sleep problems and an intervention study aimed at improving participants' sleep. The first two hypotheses were addressed in the survey, and hypotheses 3 and 4 were addressed in the intervention. To avoid confusion the methodology will be reported separately for the survey and intervention.

2.1 SURVEY

2.1.1 Participants

Individuals with learning disabilities were identified from two geographical locations using a database from a learning disability service, and all those living in residential services were excluded. The inclusion criteria for the survey were that the person was aged 18 years or above, had a learning disability and was living in their family home with parents or carers. A total of 356 people with learning disabilities and their parents / carers were invited to participate in this research through a postal survey.

2.1.2 Design

The design was a single group postal survey.

2.1.3 Measures

For the survey, individuals were asked to complete the following measures, which were

incorporated into one questionnaire (after Wiggs, 1996a; Brylewski, in press - see appendix 1):

- a) Sleep Behaviour questionnaire (Simonds & Parraga, 1982);
- b) Sleep Index (Quine, 1991);
- c) Aberrant Behaviour Checklist - Community version (Aman & Singh, 1985; 1994);
- d) A list of additional items that are known to contribute to behaviour problems.

a) Sleep Behaviour questionnaire

The sleep behaviour questionnaire was developed by Simonds & Parraga (1982) to assess children's sleep problems. Whilst acknowledging that this tool is not designed specifically for a learning disabled population, it has been used by Brylewski (in press) in her study with adults with learning disabilities, and by Wiggs & Stores (1996) in their study of children with learning disabilities. The reliability (test-retest) was reported by the original authors as between 0.83 and 1.00 for the 24 items when they were considered separately. The questionnaire has good face validity. Wiggs (1996b) tested the criterion-related validity of the questionnaire against sleep diaries for a 2 week period and concluded that it is a valid measure of subjective report of sleep problems.

b) Sleep Index

The sleep index is a measure of sleep disturbance devised by Quine (1993) for children with learning disabilities. The index uses the night settling and night waking items from the

Behavioural Screening Questionnaire (Richman & Graham, 1971) with two additional items. These items are whether parents had to attend to the person in the night, and whether the person was taken into the parents bed. Each of the four items can score either 0 (no problem), 1 (mild problem) or 2 (severe problem). Thus there is a possible range of 0-8 for total score on the index. Quine (1991) reports that internal reliability of the measure is high (Cronbach's Alpha = 0.78).

c) Aberrant Behaviour Checklist (ABC)

The Aberrant Behaviour Checklist was developed as a tool for use with people with learning disabilities that could assess treatment effects on individuals' behaviour (Aman, Singh, Stewart & Field, 1985a). The ABC has five subscales that measure different types of behaviour difficulties. These are irritability, lethargy, stereotypy, hyperactivity and inappropriate speech. The psychometric properties of this tool have been well researched. In terms of reliability, the ABC has high internal consistency for the different subscales, and has moderately high (mean = .63) inter-rater reliability (Aman et al., 1985b). It also has very high levels of test-retest reliability (.98, .99, .98, .98, .96, for the 5 subscales). The validity of the ABC has also been demonstrated, with the scores on four of the subscales being validated by behavioural observation, and evidence from cross validation with American subjects indicates that its factorial scales are valid (Aman, Richmond, Stewart, Bell & Kissel, 1987).

2.1.4 Procedure

Prior to starting this research ethical approval was sought and gained from the local ethics of research committee (see appendix 2). Approval was also sought from the Medical Director of the trust where the study was conducted. Adults with learning disabilities from two localities were then identified from the database. The database had been established for several years but with irregular updating, hence there was some concern as to the accuracy of the information. In order to try and prevent people receiving questionnaires inappropriately (e.g. if someone had died or if parents surnames were different, etc.), the two community teams in the localities in which the participants had been identified were asked to examine the lists to ensure that it was relevant for those identified to be invited to participate. One team willingly took part in this screening exercise but, unfortunately the other team refused to co-operate. However, this did not adversely affect the study because a sentence was added to the letter apologising if any of the personal details were incorrect. Once the screening exercise was completed questionnaires, consent forms and a letter explaining the study were sent to parents / carers inviting them to participate.

Both parents and the adult with a learning disability were given information sheets describing the study. These sheets were based upon those used by Brylewski (in press) in her sample of adults with learning disabilities. Although generally, parents were responsible for completing the questionnaire, it was suggested to them in the covering letter that they discuss the study with their son / daughter because it was information

about their sleep that was being requested. The letter emphasised that non-participation would not affect their use of the psychology services, neither currently nor in the future, and confidentiality was assured. The consent forms followed a standard form, as requested by the local ethics committee. A stamped addressed envelope was provided for people to reply. A reminder letter was sent to individuals within one locality who had not replied 4 weeks later in order to improve response rate.

2.2 INTERVENTION

2.2.1 Participants

A small group of individuals (six) with sleep problems were identified. The criteria for inclusion were the presence of sleeping problems and some disturbance in daytime behaviour which was considered problematic by carers. The definitions of sleep problems are outlined below.

Severe settling problem

- occurs three or more times per week;
- person takes more than an hour to settle and fall asleep;

Mild settling problem

- occurs once or twice per week;
- person settles in less than an hour;

Severe waking problem

- occurs three or more times per week;
- person wakes for more than a few minutes and disturbs the parents or goes into parents' bed or room;

Mild waking problem

- occurs once or twice per week.

Only those individuals with night waking difficulties and / or settling problems could participate in the intervention. These particular problems were chosen because they have been shown within the literature to be amenable and responsive to a behavioural intervention in children, whereas other sleep difficulties, such as sleep apnoea, have not been. A further important consideration was the willingness of carers to participate. This was assessed by adding a question to the survey that asked whether families would like help with the current sleep difficulties if available. If respondents said 'no' to this they were not contacted for participation in the intervention, irrespective of whether they fulfilled the remaining criteria. In the event of there being substantially more participants for the intervention than was possible to include, it was decided that those people with the most severe difficulties would be prioritised. This seemed ethically appropriate and likely to be of most use clinically. Additionally, if families indicated a wish for help but were not eligible to participate, it was agreed that they would be directed to the local community team or other relevant service.

In the initial stages only those people living at home with parents were eligible for the intervention. However, recruitment difficulties meant that the criteria were altered slightly to include people living in residential services. The rationale for this was that some residential services do not differ significantly from family homes, in that they do not have waking night staff, and the staff who sleep in need to sleep well, similar to parents. In this way the potential impact of the sleep problem on carers is likely to be similar to that experienced by parents. In total, seven individuals were recruited for the intervention although, due to major service restructuring, only six individuals and their carers completed the intervention. Two individuals were living at home with their families, three were living in health / social services accommodation but did *not* have waking staff, and one had waking night staff, but was considered a priority for treatment because the five other residents in the house were being disturbed by this person's nocturnal difficulties.

2.2.2 Design

Once individuals with sleep problems were identified there was an intervention study in which six single cases were studied in greater detail. The design was a multiple baseline across subjects (stepped AB design). The minimum baseline period was two weeks, with the intervention being introduced after that. The stepped design meant that the intervention for the next person was introduced at two weeks, then three weeks etc. It was agreed that two interventions would be started at each step to prevent people having to record for lengthy baselines. A minimum of three participants was necessary in order for

adequate conclusions to be drawn from the interventions (Hopkinson, 1997). Five or six participants seemed a reasonable number given the time constraints of the current study.

2.2.3 Measures

The six individuals and their carers who participated in the intervention completed all of the measures from the survey, together with the following items:

- a) Malaise Inventory (Rutter, Tizard & Whitmore, 1970), pre and post intervention;
- b) Daily sleep diary (Wiggs, 1996a);
- c) Daily behaviour diary;
- d) Aberrant Behaviour Checklist - repeated post intervention.

a) Malaise Inventory (Appendix 3)

Parents and carers were asked to complete the Malaise Inventory pre and post intervention. The Malaise Inventory has been widely used in several studies of carers of children with learning disabilities (Quine, 1993). It contains 24 binary items that ask carers about their own health during the previous few weeks. Individuals score 1 for every item answered 'yes'. A score of 5 / 6 is considered to be indicative of stress (Rutter et al., 1970) and a score of 7 or more critical, in that it suggests very high levels of stress. Rutter et al. (1970) reported high levels of test retest reliability (0.91) when 35 mothers were asked to complete the inventory twice. In addition, Quine & Pahl (1985) replicated a high correlation for test retest reliability (0.94) when 20 mothers were asked to complete the inventory on two occasions, suggesting that it is a reliable tool. It has been argued by Hirst

(1983) that the Malaise Inventory should not be used to measure stress because it does not measure one single dimension. However, Bebbington & Quine (1987) provide evidence, through completing a factor analysis on the scores of 200 mothers of children with learning disabilities, that it does measure a single factor of stress, and is therefore useful for use in research with carers of people with learning disabilities. The criterion-related validity of this tool has also been demonstrated by Quine & Pahl (1985). In addition to the empirical evidence that supports the use of the Malaise Inventory in this study, its use will also mean that the results can easily be compared with results from other studies in learning disabilities, where it has been widely used.

The Malaise Inventory was chosen because this study was initially designed to focus on family carers of people with learning disabilities. Including paid carers in the intervention did raise the issue as to whether this was the most appropriate measure to use, particularly as researchers have tended to use other measures of stress when investigating stress in paid carers of people with learning disabilities (Rose, 1993; Rose, Mullan & Fletcher, 1994). However, in order to maintain consistency across all of the six clients in the study, and because the paid carers were in a role similar to that of family members, parents and all of the paid carers were requested to complete the Malaise Inventory prior to the intervention and again upon completion.

b) Sleep Diary (appendix 4)

In order to obtain measures of the sleep difficulties and patterns experienced by the group

of six individuals, carers were asked to complete daily sleep diaries. The diary was the same as that used by Wiggs (1996a). These are not standardised measures but they are the agreed method within the literature of obtaining an accurate report of a person's sleep pattern (Espie, Lindsay & Espie, 1989; Carroll, Bliwise & Dement, 1989; Quine, 1993). It would have been preferable for two carers for each person to complete diaries for the same night, in order to assess the reliability of the sleep diary, but all carers of the six participants were on their own at night, hence measures of inter-rater reliability for this diary could not be obtained. Carroll et al. (1989) investigated the inter-observer reliability of the sleep / wake patterns of individuals living in nursing homes. Their results demonstrate high inter-rater reliability and they conclude that behavioural observations of sleep, such as sleep diaries, are a useful and reliable tool.

c) Behaviour Diary (appendix 5)

Carers were asked to keep simple daily frequency (tick) charts for the difficult behaviours displayed. The daytime behaviours that were considered problematic and necessary to monitor were agreed with all of the relevant carers, including those who cared for individuals at day centres. The completed ABC provided an extra check for ensuring that all relevant behaviours were included in the recording sheets. Every time the target behaviours occurred carers simply ticked the relevant box. Again, this is not a standardised measure of behaviour and therefore lacks reliability data, but it is widely used within clinical contexts. Given the fact that daily measures were required, and the amount of time needed for this, it was agreed to keep the recording made by carers to a minimum and

such diaries were considered appropriate. Other measures of behaviour such as the ABC, whilst aiming to provide a tool to measure behaviour change, are not devised to be used daily. Such measures would not pick up subtle changes in behaviour and are too long to be completed daily by carers. However, as noted above, the ABC was given pre and post intervention.

2.2.4 Procedure

Once individuals returned their completed questionnaires from the survey they were checked to see whether significant sleep problems and daytime behaviour difficulties existed. If there were sleep problems, and parents had ticked the box to say that they would like help, telephone contact and home visits were made to see whether they would like to participate in the intervention. The rationale for the study was discussed with families together with what participation would involve in terms of time and amount of recording. Information sheets designed for this part of the study were provided for parents and for the person that they cared for. It was agreed that families would be given 2-3 days, or more if necessary, to consider whether or not they wished to proceed. Both parents / carers and the person with a learning disability (if possible) were then asked to sign another consent form. Once parents had indicated that they wanted to participate in the intervention, but prior to actually starting it, a letter was sent to the individual's GP informing them of their wish to participate in the study, and requesting whether there was any reason why the GP thought it might not be appropriate. Copies of this letter were sent to the person's medical notes held within the learning disability trust, and to other relevant

professionals who were currently working with that person. For those individuals living in residential services, consent for participation was obtained from the team leader or manager of each house. To ensure that the whole staff teams were committed to participation, staff meetings were attended in order to explain the study and answer any questions and concerns.

As mentioned earlier, recruiting people for the intervention was problematic. This was not necessarily because sleep problems were not evident, but because some families did not perceive the sleep disturbances as problematic or amenable to change, or they felt that it was inappropriate at that time to start an intervention. Given this, it was decided to try and recruit individuals who were living in residential services. Further ethical approval was sought and received in order to use alternative methods of recruitment (see appendix 2). The two community teams were approached where the survey had been completed to ask if they knew of individuals with sleep problems. All the clinical psychologists and psychiatrists were asked whether they were aware of individuals who might benefit from this intervention. Finally, people identified in Brylewski's study (in press) as having a sleep problem were also contacted to see whether participation would be beneficial. The consent procedures used were the same as those described previously. The wording of information sheets and consent forms was changed accordingly.

Recordings of sleep and behaviour

For each client it was agreed, with carers, what daytime challenging behaviours would be

recorded. For those individuals who went to day centres, separate meetings were arranged with the staff to explain the study, and to ask their permission and co-operation for the recordings to continue at the centre. This was necessary because the study was interested in fluctuations in daytime behaviours and some of the participants spent at least seven hours of their waking time in day centres. It was agreed that the results would be presented to one day centre after the study had finished. For each person, carers were asked to complete a baseline period of sleep and behaviour diaries where nothing at all was changed in terms of sleep routines. This varied for each participant because of the stepped design and other factors beyond the researcher's control, usually holidays, but the shortest baseline was two weeks and the longest six weeks.

2.2.5 Intervention

Process and engagement

Weekly home visits, lasting approximately one hour, were completed for a 10 week period for all of the participants. This was necessary in order to maintain momentum and enthusiasm for the study, to collect the completed recordings of sleep and behaviour, and to monitor the progress of the intervention and resolve any difficulties. Carers were provided with a contact number if any difficulties arose between the scheduled meetings. Three of the participants attended day centres, hence weekly visits were also made to them in order to collect the completed behaviour charts.

After an agreed period of time, a behavioural sleep intervention was implemented in order to improve the reported sleep problems. With family carers this was easier but, for those living in residential services, written guidelines were drawn up with staff in order to ensure consistency in the approaches of the various members of the staff team (see appendix 6 for examples). It was not always possible to devise the guidelines with the whole staff teams. Therefore, at intermittent times throughout the interventions, staff meetings were attended in order to discuss progress and any difficulties. The intervention used was based upon the work of Quine (1993). In addition, behavioural techniques from the general adult literature such as stimulus control techniques (Espie, 1991) and restriction of time in bed (Lacks, 1987) were drawn upon. Obviously the exact nature of the intervention varied depending upon the individual.

Content of the intervention

Initially, from the information in the sleep diaries, the average sleep requirement for each participant was calculated. This enabled changes to be made in bed times, so that an 'optimal schedule' could be implemented (Espie & Wilson, 1993). This schedule aims to ensure that sleep is 'efficient' so that the majority of time spent in bed is spent asleep, and that individuals are not put to bed at inappropriate times. For example, if a person requires 8 hours sleep per night and gets up at 7.30 a.m., then the ideal time for going to bed would be 11.00 p.m. ($\frac{1}{2}$ an hour earlier than the difference between the number of hours required and the rising time, in order to allow for settling time). Such restriction of time in bed is acknowledged as a successful strategy for improving sleep patterns (Espie, 1991,

1992; Spielman, Saska & Thorpy, 1987). Once sleep requirements were calculated, participants' bed times were altered accordingly, in order to promote efficient sleep.

The next stage of the intervention involved using sleep hygiene techniques. These ensure that the environmental circumstances are ideal for promoting good sleep (Lacks, 1987; Lacks & Rotert, 1986). These include not going to bed until one is tired, maintaining a consistent pattern of sleep and waking times, not sleeping during the day, having some regular exercise preferably in the late afternoon, regulating caffeine intake, minimising fluid intake, and ensuring that the bedroom is comfortable in terms of noise, heat, light etc. Thus, for the participants of the current study, carers were educated about the importance of such factors in developing and maintaining good sleep patterns. Suggestions were made as to how these could be implemented for each individual.

The use of positive routines was introduced for participants prior to going to bed. The use of a regular pre-sleep routine is extensively reported as a successful stimulus control technique for improving sleep (Hewitt, 1985; Lacks, 1987; Milan et al., 1981; Richman et al., 1985; Quine, 1993). Stimulus control aims to help individuals associate particular stimuli with bed and sleep. Thus, for each participant, an individualised routine was devised that would help cue them into the fact that sleep and bed were approaching. This included ensuring stimulation levels were not high before bed, giving people relaxing baths immediately before bed, pyjamas put on just before bed (i.e. not at 7.00 p.m. just because it is convenient), teeth cleaning etc.

A further vital part of each intervention was a functional analysis of the night waking or settling problems. This was obtained from the sleep diaries and from interviews with significant carers. Once this was established, strategies were developed to ensure that nocturnal activities were not reinforced. For example, one participant was habitually offered food and drink if he woke in the night and he seemed to enjoy the one-to-one attention which was not provided throughout the day. Another person had a cup of tea made for her and was given a 'chat' to help them back to sleep. Another person used to shout loudly about issues that had been concerning her the day before. In these cases reinforcers were removed, e.g. food, drinks, attention etc., and alternatives provided throughout the day, such as ensuring that the client received some one-to-one attention during the day, and providing time to discuss a client's concerns. Consistent responses were also agreed in order to deal with night time disruptions. Finally, for one participant, positive reinforcement (a sticker chart) was used in order to reward her appropriate sleep behaviour, a technique shown to be useful with children with learning disabilities (Quine, 1993).

3. RESULTS

For clarity, the results of the survey and the intervention will be considered separately. For each section demographic information is presented initially, followed by investigations of each of the hypotheses. Percentages reported in the results exclude missing data. All statistical analyses were performed using SPSS for Windows.

3.1 SURVEY - DEMOGRAPHIC INFORMATION

3.1.1 Response Rate

Of the total 356 questionnaires sent to families, 110 (30.9%) were returned. Of these 65 (18.25% of the total sent) were completed. Only 64 were used in the analysis because one was aged 14 and had to be excluded. The remaining 45 comprised 29 individuals who chose not to participate, 10 people who were no longer living at the address, three who had been wrongly put onto the database, i.e. did not have children with learning disabilities, two individuals who had moved into residential care, and one person who was deceased.

3.1.2 Sample characteristics

Forty (62.5%) of the 64 individuals were male and 24 were female. The mean age of the sample was 32.6, with a range of 18-65 years. Table 1 shows the different diagnoses that the families had been given to explain their child's learning disability. The majority of

families (55.6%) did not have a diagnosis. The most common known reason for the learning disability was Down's syndrome (12.7%), followed by cerebral palsy.

Table 1 - Causes of participants' learning disability.

Diagnosis	Number of sample with that syndrome / diagnosis (%)
Autism	1 (1.6%)
Birth Trauma	4 (6.3%)
Cerebral Palsy	5 (7.9%)
Down's Syndrome	8 (12.7%)
Hydrocephalus	2 (3.2%)
Klinefelter's Syndrome	1 (1.6%)
Rett's Syndrome	2 (3.2%)
Spina Bifida	1 (1.6%)
Unknown	35 (55.6%)
Other	4 (6.3%)

The questionnaires were completed by various family members on behalf of the person with a learning disability. Thirty six mothers, 12 fathers, five siblings and nine other family carers completed the questionnaires (this information was missing for the remaining three). In terms of daytime occupation the majority (n=39) went to day centres. Nine went to college, two were in employment, eight had no daytime occupation at all, four did other activities and details were missing for six people. Twenty three out of 62 participants suffered from epilepsy. It was not possible to ascertain an accurate assessment of each participant's level of abilities. However, respondents were able to report on levels of language and speech. Table 2 shows the number of people with the various amounts of speech. Over half of the sample (62.3%) were able to use full sentences. This suggests that the sample may be biased towards individuals with less severe disabilities.

Table 2 - Participants' communication abilities.

Amount of speech	Number of participants (%)
None	7 (11.5%)
Few Single Words	5 (8.2%)
Few Phrases	11 (18.0%)
Full Sentences	38 (62.3%)
Total	61 - 3 missing

3.2 SURVEY - HYPOTHESES 1 AND 2

Hypothesis 1

It was predicted that prevalence rates of sleep problems in adults with learning disabilities living at home with their families would be similar to those reported in adults with learning disabilities living in residential services.

3.2.1 Prevalence of sleep problems

Settling Problems

Twenty two (34.38%) people reported some difficulties with their son / daughter settling to sleep at night. The extent of the difficulties varied, with the majority (n=16) of those with a settling problem being able to settle themselves off to sleep. This of course does not mean that parents are not disturbed by such settling problems. Four participants required parents' help to settle them to sleep, whilst two participants were reported as having major difficulties settling to sleep. The extent of the settling problems are listed below in Table 3. Of those who did report settling problems (n=22), 50% experienced problems three or

more times per week. The length of time taken for individuals to settle to sleep also varied greatly, with 10% of participants for whom a problem was reported taking more than one hour to settle. Nine participants took longer than a few minutes, but within one hour, to settle. The frequency with which these difficulties occurred can be seen in Table 4. Table 5 illustrates the length of time taken to settle to sleep for those with a settling problem.

Table 3 - The extent of settling problems.

Extent of settling problem	Number of people with that problem(%)
No Problem	40 (63.5%)
Problem- Settles Self	16 (25.4%)
Problem - Needs Parents To Settle	4 (6.3%)
Big Problems- Cries, Comes Downstairs Etc.	2 (3.2%)
Missing	2

Table 4 - Frequency of settling problems.

Frequency of settling problems	Number of participants who experience problems at each frequency. (%)
No problem	40 (65.6%)
Less than 1 per month	6 (9.8%)
2-4 times per month	2 (3.3%)
1-2 times per week	2 (3.3%)
3 or more times per week	2 (3.3%)
Daily	9 (14.8%)
Missing	3

Table 5 - Time taken to settle to sleep.

Time taken to settle to sleep	Number of participants. (%)
Not applicable	38 (64.4%)
Few minutes	6 (10.2%)
Up to half an hour	5 (8.5%)
Up to 1 hour	4 (6.8%)
Up to 2 hours	2 (3.4%)
3 hours or more	4 (6.8%)
Missing	5

Waking Problems

Thirty four (56.7%) parents reported that their son / daughter usually woke in the night. The frequency and duration of such wakings varied amongst the participants. Twelve individuals woke every night, with half of all of those who woke doing so three times or more a week. Table 6 shows the frequency of night wakings. Of those who did wake, seven individuals woke three times or more each night. In total 15 participants woke at least once each night. The majority of participants (n=18) took only a few minutes to settle after waking. Nine people took up to half an hour to settle again. Three individuals took more than an hour to settle back to sleep. Two participants could take three or more hours to settle back to sleep. Tables 7 and 8 respectively show the number of times each night that a person woke, and the length of time to resettle them.

Table 6 - Frequency of waking problems.

Frequency of waking problem	Number of participants (%)
No problem	24 (41.4%)
Less than once per month	6 (10.3%)
About 1 per month	3 (5.2%)
2-4 times per month	3 (5.2%)
1-2 times per week	5 (8.6%)
3 or more times per week	5 (8.6%)
Daily	12 (20.7%)
Missing data	6

Table 7 - Number of times each night that person wakes.

Number of wakings each night	Number of participants (%)
No problem	24 (42.1%)
Once	17 (29.8%)
Once or twice	8 (14.0%)
About 3 times	4 (7.0%)
4 or more times	3 (5.3%)
Missing	7

Table 8 - Time taken to settle after waking in the night.

Time taken to re-settle	Number of participants (%)
No problem	24 (43.6%)
A few minutes	18 (32.7%)
Up to half an hour	9 (16.4%)
Up to 1 hour	1 (1.8%)
Up to 2 hours	1 (1.8%)
3 or more hours	2 (3.6%)
Missing data	9

The above Tables provide valuable and detailed information with regard to the wide range and nature of the sleep problems experienced by this population. In terms of the definitions of sleep problems discussed in the Introduction, eight respondents had severe waking problems, five had mild waking problems, three had severe settling problems, and two had

mild settling difficulties. Table 9 shows the number of the sample who have mild or severe settling or waking problems (after Quine, 1992). There appears to be an obvious discrepancy between the low number of participants fulfilling the definition criteria and those previously considered as having sleep problems by their carers. The reason for this is that the definitions frequently required two conditions to be met. There were a large number of individuals who fulfilled one part of the definition but not the other. Nine participants had settling problems and 10 participants had waking problems that fulfilled only one part of the definition. Such individuals are not included within Table 9.

Table 9 - The number of participants with sleep problems using Quine's (1992) definitions.

Mild settling problems	2 (3.13%)
Severe settling problems	3 (4.69%)
Mild waking problems	5 (7.81%)
Severe waking problems	8 (12.50%)

Sleep index

The sleep index is a numerical measure that is partly derived from the definitions of sleep problems (Quine, 1991), with a higher score indicating a more severe sleep difficulty. In Quine's study of children with learning disabilities, the mean score was 2.8 (SD = 2.5, range 0-8). Of the four items that comprise the index, the waking and settling items each score a two if they fulfil the severe definition and one if they fulfil the mild definition. The mean score with the sleep index for this sample was one, with a standard deviation of 1.69

and a range of 0 - 6. Twenty five (39%) of the sample scored at least one on the index, with seven participants scoring four or more.

Other sleep difficulties

Three individuals did not routinely sleep in their own bed. Six participants spent some time in the parental bed. This occurred twice a week or more for two participants. One person stayed there for just a few hours, whereas two participants stayed most of the night. Five individuals woke before 5 a.m. several times per week, and eleven others woke this early but on a less frequent basis, i.e. two to four times per month or less. Carers reported that 21.7% (n=13) of participants were not well rested when they woke in the morning, with 29% (n=18) reporting that the person with a learning disability woke in a bad mood. Twenty two (35.5%) participants appeared tired in the morning. Of these 22, the majority (12) were considered to be most tired during the following evening.

Twenty three participants slept during the day. The duration of the sleep varied, but the average time spent asleep during the day was 16.53 minutes, (SD = 59, range 10-420 minutes). Eight carers had in the past received some advice or treatment for their son's / daughter's sleep problems. Six of those offered treatment had received medication and two had received psychological help. Six carers rated the advice or treatment as helpful. Four carers gave a reason for why they considered the advice or treatment helpful. For all four participants the advice or treatment had resulted in a resolution of the sleep problem.

Reasons for the treatments being unhelpful were that they did not work, or that there were adverse effects (usually daytime drowsiness with medication).

Parents' Opinion about the sleep problems

Fourteen (21.9%) families considered that sleep was a problem for their son / daughter. The average length of time for which the sleep problem had been evident was 4.5 years (SD = 10.88). The range was great with one person having had sleep problems for just six months while another for 43 years. Of those 14, 10 indicated an interest in receiving some help to alleviate the sleep problem. Mothers most frequently attended to their son / daughter during the night. Eighteen carers felt that they themselves did not get sufficient sleep, with 11 of these saying that the reason for this was that their son / daughter with a learning disability woke them up. In total 21 carers reported that their son / daughter had had a sleep problem in the past. Of these 21, nine still had difficulties that met the criteria for Quine's definition of a sleep problem.

Summary

In total, 7.8 % (n = 5) of the sample of 64 had a settling problem, defined as either mild or severe. In contrast 20.3 % (n = 13) had a waking problem, defined as either mild or severe. This suggests that sleep problems in adults with learning disabilities who live at home are not as prevalent as sleep problems are in those people with learning disabilities who live in residential services or in children with learning disabilities. Although there is a discrepancy between the prevalence figures for adults with learning disabilities, the greater amount of

waking problems in comparison to settling problems, as reported by Brylewski (in press), is also evident in this sample. The results from this study suggest a higher overall prevalence than the 15% reported by Espie & Tweedie (1991), but not as high a prevalence as for those who live in residential services. If one considers prevalence figures for settling and waking problems generally (34.48 % and 56.7% respectively), i.e. including those who did not fulfil the criteria of the definition, these figures more easily replicate the findings from residential services. However, this study used the sleep definitions previously described to report prevalence figures, and subsequently this hypothesis was not confirmed from these results.

Hypothesis 2

It was predicted that there would be a stronger relationship between sleep problems and daytime behaviour problems in adults with learning disabilities who live at home, than between a number of other possible variables and behavioural disturbance.

3.2.2 Influence of sleep on behaviour problems

Twenty one (35%) carers reported that if the person with a learning disability had a poor night's sleep then their behaviour was difficult the following day. Three carers felt that behaviour was worse in the morning, four considered it worse in the afternoon, six reported that evenings were when behaviour was particularly difficult, and the majority (8) felt that it made no difference and behaviour was difficult all day following a poor sleep.

This anecdotal evidence provides some preliminary support for the hypothesis that difficult daytime behaviour has some relationship to poor sleep.

Stepwise multiple regression analyses were completed to assess which variables of sleep problems, and other factors known to contribute to behaviour difficulties, best predicted daytime behavioural disturbance. A stepwise analysis allows one to consider the individual predictive influence of a number of factors on behaviour. The scores on each of the five subscales and the total score on the Aberrant Behaviour Checklist were the dependent measures in the regression analyses. The independent measures in each analysis were one of six different sleep difficulties, epilepsy, poor communication, presence of physical disabilities, sensory impairments and particular diagnosis of learning disability. A regression was completed for each of the five subscales and for the total score on the ABC, and separate analyses were performed with each type of sleep difficulty with all of the remaining independent measures included in each analysis. In total, 36 multiple regressions were completed.

Mild settling problems were the best predictors of irritability, lethargy, hyperactivity and the total score on the ABC, rather than the other factors that are known to affect behaviour disturbance. Any form of settling problem, that is either mild or severe, were the best predictors of behaviour difficulties, in particular lethargy and hyperactivity. Waking problems in whatever form were not predictive of behavioural disturbance. Poor communication was also a predictor of scores on the hyperactivity subscale. The other

factors known to influence behaviour disturbance, such as sensory impairments, physical disabilities, epilepsy and autism were not found to be good predictors of behaviour difficulties. Table 10 shows the results of each regression. Residuals from each regression were calculated and distribution tested using Kolmogorov Smirnov test. However, caution is required when considering the sleep factors that are shown to be significant predictors of daytime behaviour problems because not all of the residuals demonstrated normality.

Table 10 - The t values and degrees of freedom for each regression completed. An empty box indicates that none of the expected variables were predictors of behaviour difficulties.

Sleep problem	Irritability subscale	Lethargy subscale	Stereotypy subscale	Hyperactivity subscale	Inappropriate speech subscale	Total
Mild settling problem	2.28* d.f. 55	4.05** d.f. 55		4.66*** d.f. 54		3.99*** d.f. 55
Severe settling problem						
Settling problem as defined by either mild or severe		2.35* d.f. 55		2.770** d.f. 53		2.381* d.f. 55
Mild waking problem						
Severe waking problem						
Waking problem as defined by either mild or severe						

* $p < .05$; ** $p < .01$; *** $p < .001$

Note those results in **bold** are the regressions where the residuals demonstrated a normal distribution

As mentioned previously there were 19 participants who had some form of sleep disruption that only fulfilled one part of the criteria for each definition. Further regressions were completed to test whether this type of sleep problem successfully predicted daytime behaviour. Kolmogorov Smirnov tests were performed to investigate whether the distributions of the residuals for each regression were normal. Having a sleep disturbance, although one that only fulfilled one part of the definition used in this study, did not predict daytime behaviour disturbance. The best predictor of scores on the hyperactivity subscale was poor communication ($t = 2.31$, d.f. 54, $p < .03$, for those with other settling problems; $t = 2.31$, d.f. 54, $p < .03$, for those with other waking problems). Caution is needed when interpreting these results because the residuals were not normally distributed. There were no other predictors for the other four subscales.

Summary

The influence of sleep problems on daytime behaviour disturbance remains unclear. The results show that settling problems were the best predictors of daytime behaviour disturbance, in terms of irritability, lethargy and hyperactivity and the total score on the ABC. However, settling problems did not significantly predict stereotypical behaviours or inappropriate speech. The lack of normality of the data compounds these conclusions further, and suggests that settling problems were the best predictors of scores on the hyperactivity scale and the overall level of behaviour disturbance. The hypothesis can not, therefore, be accepted because sleep problems in general do not appear to have a great

influence on daytime behaviour problems. The relationship between settling problems and hyperactivity and overall total score on the ABC is highly specific.

3.3 INTERVENTION - DEMOGRAPHIC INFORMATION

N.B. to maintain confidentiality all names have been changed

Of the ten people who indicated on the survey that they would like help with their son's / daughter's sleep problem, none were included in the intervention. The reasons for this varied, including the fact that the inclusion criteria were not fulfilled, because potential participants did not feel that it was an appropriate time, or because they felt unable to complete the recordings and maintain consistency in implementation. As a result the six participants for the intervention were recruited using the alternative methods previously described. Five were recruited from professionals in community teams and one was obtained from Brylewski's study. The study used single case design, and therefore each participant will be described briefly. The sleep problems described are those reported by carers and not those recorded during the baseline, which are described later. The behaviour difficulties are reported in terms of the subscales of the ABC. Aman & Singh (1994) use a cut off above the 85th percentile to indicate an extreme score on a particular subscale of the ABC, whilst acknowledging that this is not a definitive level of difficult behaviour. However, not all of the participants reached such extreme scores. Not reaching the 85th percentile does not mean that the participant's behaviour was not difficult. All of the behaviours reported on the ABC were in some way problematic to carers and parents.

Tables 13 and 14 summarise actual scores on each of the subscales of the ABC, indicating when the scores exceeded the 75th and 85th percentile.

Jane

Jane was a 42 year old woman with severe learning disabilities, who lived in a social services residential home. Jane usually woke about three times every night, disturbing the other person with whom she lived and the member of staff who was sleeping in, by shouting out. The difficulties had been evident for approximately seven years. Staff requested help because their sleep was being disrupted and this deprivation was causing them to experience stress. The main behaviour problems were Jane's inappropriate speech and her lethargy. The focus of the intervention was to reduce the number of wakings and to encourage Jane not to shout during the night.

Mary

Mary was a 23 year old woman with very severe learning disabilities, who lived in a shared house. Mary's difficulties were that she could take up to two hours to settle to sleep. These settling difficulties would occur at least twice each week. This resulted in Mary's house-mate and the staff who were sleeping in being disturbed. Mary's settling problems had been experienced throughout her life. Staff wanted to participate in the intervention because lack of sleep was stressful for them and also because they were concerned about the effect on Mary of having disrupted sleep. The aim of the intervention was to decrease

the time taken for Mary to settle to sleep. The highest scores on the ABC was Mary's hyperactivity.

Wendy

Wendy was a 37 year old woman who was living at home with a family carer. The main difficulties were that she woke about three times each night and could take up to an hour each time to settle back to sleep. Wendy's carer was disturbed by Wendy, which resulted in her feeling tired during the day. These problems had been evident for all of Wendy's life. Wendy's carer wanted to reduce the number of times that Wendy woke as well decreasing the overall time spent awake. Wendy's main behaviour problems were lethargy and irritability.

Susan

Susan was a 70 year old woman with very severe learning disabilities, who shared residential accommodation with one other person. Susan would wake up to four times per night several times a week. She would enter the sleeping-in room of staff and disturb them. Staff were exhausted, particularly as they were expected to work the morning shift following a disturbed night. The focus of the intervention was to reduce the number of night wakings. Susan's main behaviour problems were irritability and hyperactivity.

John

John was a 55 year old man with very severe learning disabilities, who shared a house with

five other people. John woke every night, frequently four or more times each night. There were waking night staff, so staff were not disturbed, but the others living in the house were disturbed. Additionally, his whole sleep pattern was disrupted. Sometimes he did not sleep at all for a 24 hour period, then he would sleep for ten hours during the day. John had had sleep problems since childhood. It was agreed that the aim of the intervention was to increase the actual amount of sleep that John had at night. His main behaviour difficulties were hyperactivity, irritability and stereotypical behaviour.

Peter

Peter was a 24 year old man with very severe learning disabilities, who lived at home with a family carer. Peter woke four times or more every night. His carer was exhausted as he required her help in settling him back to sleep. Peter has had sleep problems since he was a baby. Peter's carer wanted to reduce his number of wakings and to try and encourage him to settle without her help. There was a large discrepancy between the ABC scores for home and the day centre. At the day centre the main difficulties were irritability, hyperactivity and stereotypical behaviours

3.4 INTERVENTION - HYPOTHESES 3 AND 4

Hypothesis 3

It was predicted that a successful sleep intervention for adults with learning disabilities would result in a subsequent improvement in daytime challenging behaviour (for a small

group of clients).

3.4.1 Do improvements in sleep result in improvements in daytime challenging behaviour?

Statistical analysis of single case data remains controversial (see Kazdin, 1984, for a detailed review). Visual inspection is considered adequate in many circumstances (Wilson, 1995) and it has been noted that statistical analyses can best be considered as a way of describing clear effects that are evident from visual inspection (Sunderland, 1990 in Wilson, 1995). Visual inspection of the current data indicated no clear trends in the behavioural recordings; hence the criteria for statistical analyses was not reached (Hopkinson, 1997). As a result visual inspection was considered to be the most appropriate method of analysis in the current study.

In order to be able to test the hypothesis that a successful sleep intervention would result in an improvement in daytime behavioural disturbance, it was necessary to demonstrate that a successful sleep intervention had been completed and that there had been an improvement in participants' sleep. The progress of each participant will be considered separately. Tables 11a & 11b provides a summary of the progress of each participant, describing the average number of wakings, time spent awake during the night, total amount of sleep and time taken to settle to sleep.

Jane

During the baseline Jane's average number of wakings each night were 1.85, with Jane

waking for approximately 25 minutes on each occasion. Following intervention her average number of wakings each night had reduced to 0.77, with Jane waking for approximately nine minutes (usually to go to the toilet). Her average amount of sleep had increased from 7.21 to 8.52 hours each night and her settling time had reduced by 14 minutes.

Mary

Mary was the exception from the other five in that it appears that her sleep had deteriorated. During the baseline Mary seemed to make a spontaneous recovery (to the surprise of the staff), with her settling time averaging 35 minutes. This is likely to be attributable to medication she was taking for an illness. Despite this she remained in the study because staff felt that this would not continue, which it did not. Her average settling time post intervention was 58 minutes, which suggests a deterioration. However, the total time of the intervention was eight weeks and, when comparing averages from the first four weeks and the latter four weeks, there was a decrease from 67 to 43 minutes settling time. As shown in the graphs, improvements in Mary's sleep occurred towards the end of the intervention. Comparisons between intervention and baseline phases requires caution. Subjectively staff felt that Mary was much calmer at bedtime and that even if she was not asleep she was quiet and remained in bed, which she had never done before.

Wendy

Wendy was waking on average 1.57 times each night during the baseline period, for 53

minutes each time. Following the intervention her average number of wakings each night was 0.94, with the duration of the waking period more than halved, to 23 minutes. The total amount of sleep each night had also increased, from 7.88 to 8.97 hours.

Susan

Throughout the baseline Susan was waking on average 2.3 times each night, for 26 minutes. Post intervention the number of wakings had reduced to once each night for on average 17 minutes. Susan's overall sleep requirement remained stable throughout the study.

John

John slept for approximately 2.85 hours each night during the baseline, usually waking an average of 2.05 times for an average of 71.11 minutes. He also had three nights during the four week baseline period when he did not sleep at all. Following the intervention John was sleeping for an average of 5.08 hours each night, waking on average 1.79 times, for an average of 55.3 minutes. He had not had any completely sleepless nights throughout the six week intervention.

Peter

Peter was waking on average 2.03 times each night during the baseline, for an average of 60 minutes. Peter's progress was not so successful or rapid and post intervention he woke

1.73 times each night, for an average of 47 minutes. His overall amount of sleep remained constant.

Table 11a & 11b - Participants progress on various sleep measures. Pre measures are provided to aid easy comparisons.

Participant	Average number of wakings each night - baseline	Average number of wakings each night - post intervention	Average time awake each night - baseline (minutes)	Average time awake each night -post intervention (minutes)
Jane	1.85	0.77	24.55	9.71
Mary	n/a	n/a	n/a	n/a
Wendy	1.57	0.94	53.25	23.75
Susan	2.30	1.00	25.91	17.56
John	2.05	1.79	71.11	55.30
Peter	2.03	1.73	59.63	47.80

Table 11b.

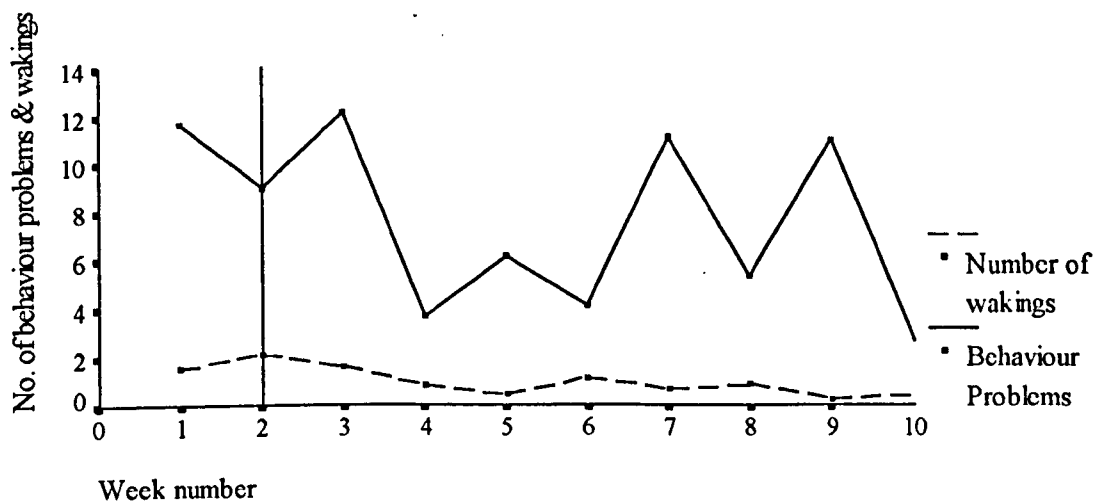
Participant	Amount of sleep - baseline (hours)	Amount of sleep - post intervention (hours)	Time taken to settle to sleep - baseline (minutes)	Time taken to settle to sleep - post intervention (minutes)
Jane	7.21	8.52	47.50	33.92
Mary	8.45	8.55	35.00	58.02
Wendy	7.88	8.97	n/a	n/a
Susan	7.24	7.88	n/a	n/a
John	2.85	5.08	n/a	n/a
Peter	6.05	6.15	n/a	n/a

For four of the six participants there was some clinical improvement in either the total amount of sleep that was experienced or a decrease in the number of wakings, with the exception of Peter and Mary. Given this, visual inspection of the data of recordings of challenging behaviours and sleep problems was completed in order to see whether the number of incidences of challenging behaviour decreased as sleep improved. Figures 1-6

illustrate the extent of the intervention effect, and also the frequency of occurrence of daytime challenging behaviour. The graphs show the daily average for each variable for each week. Different sleep variables, e.g. number of wakings, total amount of sleep, are shown in the graphs depending upon what was considered the main sleep problem by staff. In contrast to the other graphs, an upward slope for John indicates improvement because this graph shows total amount of sleep. The behaviours recorded for each participant were those behaviours difficulties that were considered problematic for their carers, i.e. each participants had individualised behavioural recordings. The graphs are shown in the stepped order in which the intervention was completed. The single line crossing the horizontal axes separates the baseline from the intervention.

Graph showing incidence of behaviour problems and number of wakings

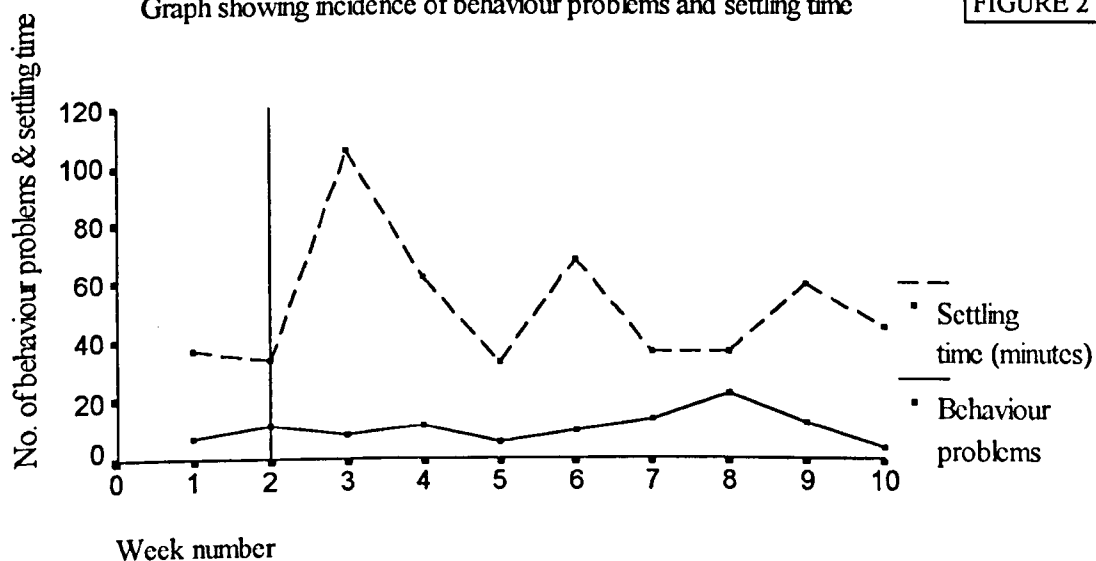
FIGURE 1



Mary

Graph showing incidence of behaviour problems and settling time

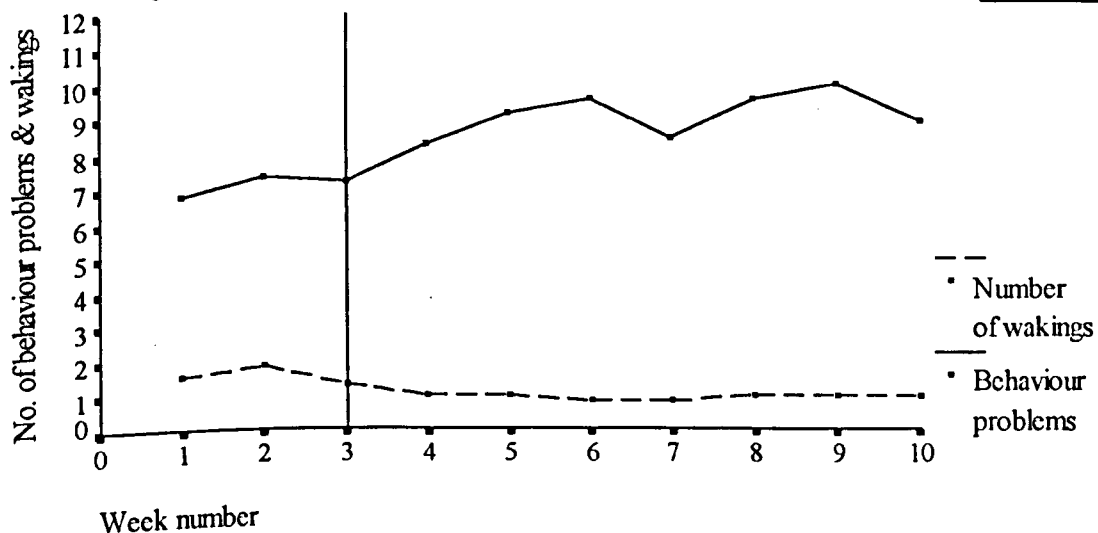
FIGURE 2



Wendy

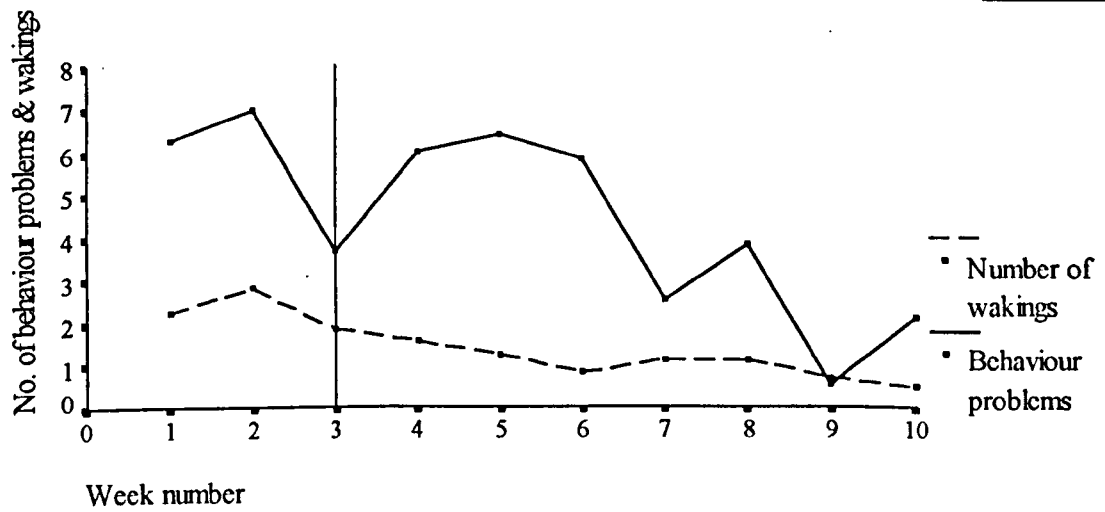
Graph showing incidence of behaviour problems and number of wakings

FIGURE 3



Graph showing incidence of behaviour problems and number of wakings

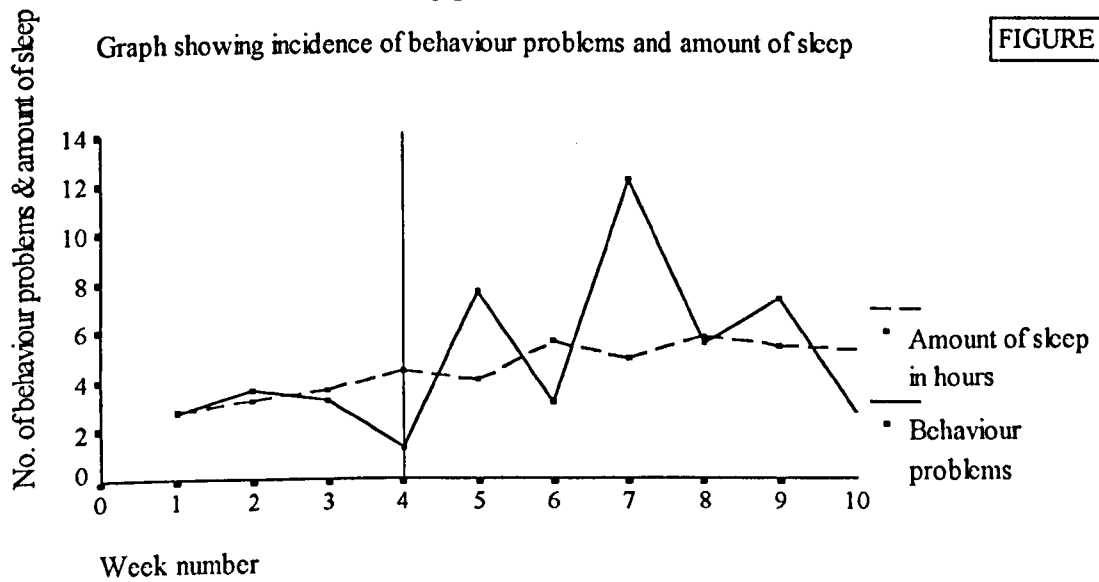
FIGURE 4



John

Graph showing incidence of behaviour problems and amount of sleep

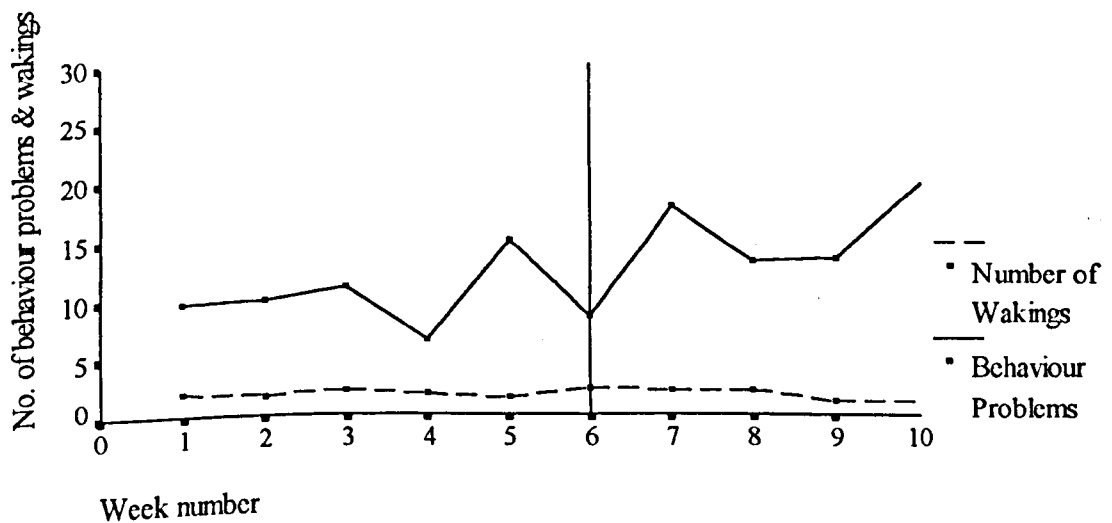
FIGURE 5



Peter

Graph showing incidence of behaviour problems and number of wakings

FIGURE 6



Overall there was little evidence that difficult or challenging behaviour changed significantly following a sleep intervention. Indeed, Susan is the only participant who showed a trend towards a decline in the occurrence of difficult behaviour towards the end of the intervention. However, the period of the intervention finished before it was possible to be certain that this downward trend would continue and be maintained. Although beyond the scope of this study, it is likely that extended monitoring would be required to assess whether the sleep intervention has a long term transition effect on behaviour. For Wendy, John and Peter there is some suggestion that the occurrence of behaviour difficulties tended to increase following the sleep intervention, although the exact nature of this relationship remains unclear. Peter showed little improvement in his sleep, yet his behaviour problems deteriorated. If his sleep problems had worsened, then one would question whether this influenced the deterioration in behaviour, in that the converse of the hypothesis could also be true. That is a deterioration of sleep problems could cause behaviour problems to worsen. However, the fact that his sleep problems remained fairly constant suggests that a simple predictive relationship between the two variables in either a positive or negative direction does not exist. If the variables were related in a causal way one might expect that if one variable remained constant then so would the other. From these graphs it can be concluded that sleep does not appear to be the key factor in daytime behaviour disturbance. Unfortunately, all of the data for all of the participants shows high variability in responding, particularly behaviour scores, hence conclusions on the trends described require caution.

Whilst it was not possible to draw any definitive conclusions from the daily recordings regarding the influence of sleep interventions on daytime behavioural disturbance, it was important to assess whether changes had occurred in participants' scores on the ABC. It is possible that changes could have occurred in behaviour and that this was not being monitored (for a variety of reasons) on the daily recording sheet. Additionally, behaviours other than those recorded may have been affected by the sleep intervention. Wilcoxon tests were performed on participants' subscale and total scores on the ABC, pre and post intervention, to see whether the changes in behaviour scores were statistically significant. The analyses was weighted to account for the fact that Peter and Mary had more than one ABC completed. However, these results show that the changes in behaviour scores were not significant, which supports the analysis from the visual inspection. Table 12 summarises the results of the Wilcoxon tests. If a discrepancy had occurred between the conclusions from the daily behaviour recordings and the scores on the ABC, then it would have raised questions as to the accuracy of either of these as a tool of measurement. It is noteworthy that for each participant there was a decrease in at least one subscale on the ABC. The size of the decrease varied considerably with a minimum decrease of one and a maximum decrease of 10. Table 13 shows the changes in participants actual scores on each subscale. Although a total score on the ABC is not widely used, for clarity, Table 14 shows the changes in the total score of the ABC for each participant, which demonstrates the overall change.

Table 12 - Wilcoxon results comparing the pre and post scores for each subscale and the total score on the ABC.

Subscale	T value	Significance
Irritability	5	n.s.
Lethargy	2.5	n.s.
Stereotypy	3	n.s.
Hyperactivity	2	n.s.
Inappropriate speech	3	n.s.
Total score	5	n.s.

n.s. = non significant at 5%

Table 13 - Changes in behaviour scores on the Aberrant Behaviour Checklist, with each subscale reported separately.

Participant	Irritability		Lethargy		Stereotypy		Hyperactivity		Inappropriate Speech	
	pre-intervention	post-intervention	pre-intervention	post-intervention	pre-intervention	post-intervention	pre-intervention	post-intervention	pre-intervention	post-intervention
Jane	15	19	<i>15</i>	8	4	5	6	8	9	8
Mary (1)	9	<i>19</i>	8	<i>14</i>	5	6	<i>19</i>	22	1	0
(2)	11	10	7	6	0	0	13	8	0	0
Wendy	<i>17</i>	14	<i>16</i>	<i>12</i>	4	1	3	2	0	0
Susan	11	2	7	6	4	2	10	7	0	0
John	12	<i>16</i>	9	8	9	6	21	21	3	3
Peter (1)	1	1	1	1	0	0	12	12	0	0
(2)	<i>16</i>	8	10	11	11	7	43	36	0	3
(3)	15	5	8	1	9	3	36	33	1	2

Bold denotes when the score > 85th percentile.

Italics denotes when the score > 75th percentile, but < 85th percentile.

N.B. Mary and Peter have more than one score on each subscale because key workers at day centres also completed ABC.

Table 14 - Changes in participants total scores on the ABC pre and post intervention.

Participant	Total score on the ABC - Pre-intervention	Total score on the ABC - Post-intervention
Jane	49	48
Mary (1)	42	61
(2)	31	24
Wendy	40	29
Susan	32	17
John	54	54
Peter (1)	14	14
(2)	80	65
(3)	69	44

N.B. Mary and Peter have more than one score because key workers at day centres also completed ABC.

Summary

These results do not lend support to the hypothesis that improvement in sleep results in a subsequent improvement in daytime difficult behaviour. The relationship between sleep disturbance and daytime behaviour disturbance remains unclear for the six participants, suggesting that a simple linear relationship does not exist between these two variables.

Hypothesis 4

It was predicted that carer stress would reduce as a result of alleviating sleep difficulties.

3.4.2 Impact of sleep intervention on carer stress

Carers scores on the Malaise Inventory were compared pre and post intervention. For some participants, where a whole staff team completed Malaise Inventories, the scores were weighted to prevent there being a bias in favour of those participants who had several people completing the Inventory. The average score on the Malaise Inventory

prior to the intervention starting was 3.64 (SD = 3.31), with a range of 0-13. The average score upon completion of the intervention was 2.70 (SD = 2.48), with a range of 0-10. A paired t-test was used to test whether the changes in overall stress scores was significant following a successful sleep intervention ($t=.42$, d.f., 5, NS). These results show that carer stress did not decrease significantly following the intervention. A t-test was used instead of a Wilcoxon because the Malaise scores using the Kolmogorov Smirnov test demonstrated normality. It is interesting to note that, despite the fact that the changes in stress scores were not statistically significant, for five of the participants, carers subjectively reported that they experienced less stress and this was because the intervention had, for the person they cared for, been successful.

Summary

These results do not support the hypothesis that carer stress would reduce with a successful sleep intervention, despite qualitative reports from carers that this had actually been the case.

4.0 DISCUSSION

The discussion briefly summarises the results of this study in relation to the specific hypotheses investigated. Consideration is then given to methodological constraints. The implications of the results are then discussed with regard to the theoretical and clinical context and the direction for future research. This section concludes by outlining what the study has achieved.

4.1 SUMMARY OF RESEARCH FINDINGS

4.1.1 Prevalence of sleep problems

Individuals with learning disabilities who live at home with their families have overall prevalence figures of 28% for sleep problems, which is higher than those experienced within the general population (Lacks, 1987). With respect to learning disabilities the prevalence of sleep problems for adults who live at home is considerably less than that for those individuals who live in residential accommodation (Brylewski, in press). However, it is worth noting that there were substantially more people reporting sleep problems who did not meet the criteria for the definitions used in this study. This could suggest that using such definitions could underestimate the prevalence of sleep difficulties in people with learning disabilities who live at home.

4.1.2 Relationship between sleep problems and daytime behaviour disturbance

The relationship between sleep problems and daytime behaviour disturbance remains unclear. The survey demonstrated a significant relationship between settling problems and scores on the hyperactivity subscale, and the overall score on the ABC. Additionally settling problems were predictive of lethargy and irritability, but because the data did not conform to a normal distribution, these results must be interpreted with caution. Waking problems were not predictive of any form of behaviour difficulties. This suggests that the relationship may be very specific in terms of the type of sleep problems that predict particular forms of daytime behaviour problems. The intervention did not offer much support for the hypothesis that these two variables are related. With the exception of Susan, who did demonstrate a reduction in behaviour difficulties following an improvement in her sleep, none of the other participants' behaviour problems reduced after the sleep intervention. It is worth noting that although the survey showed no evidence for waking problems being predictive of behaviour difficulties, Susan's sleep problem was night waking. The increases in problematic behaviour that occurred with three participants suggest that factors other than sleep are more important influences on behaviour problems. It can not be concluded, therefore, that sleep can generally be considered as a key factor in daytime behaviour disturbance, although the survey evidence suggests that specific settling problems might be. The mixed results advocate the necessity for further research before definitive conclusions can be drawn.

4.1.3 Carer stress and sleep problems

Carer stress did not reduce significantly following a successful sleep intervention. Despite this, it is worth noting that several carers subjectively reported that they *felt* less stressed since there had been some improvement in the sleep problem of the person that they cared for. Of interest to note, is that most of the carers (including those of Peter and Mary, who both showed little improvement in sleep) all reported that weekly visits from a professional who had an interest and understanding of sleep problems had a positive impact on their subjective experience of stress, irrespective of the change that had occurred in sleep patterns.

4.2 METHODOLOGICAL ISSUES

The following methodological issues need to be considered when interpreting and applying the results of the current study.

4.2.1 Response Rate

The total number of questionnaires available for analysis was fairly small considering the number initially sent out, particularly in comparison to the research of Wiggs & Stores (1996) and Brylewski (in press). Caution is therefore required when considering prevalence rates, because it is possible that those who did respond were in some way unrepresentative. Limitations of the study prevented this, but it would be advantageous to have details on non-respondents' reasons for not completing the questionnaire. It could be

that parents of a person with a sleep problem were more willing to participate in a study that was of particular relevance to their concerns (Wiggs & Stores, 1996). Further support for the suggestion that the sample could be unrepresentative was the high number of learning disabled participants who used full sentences in their communication. It is possible that those with more severe learning disabilities were not well represented and that the prevalence figures may be biased towards those individuals who were less disabled. Additionally, the factors known to contribute to behaviour difficulties, for example, epilepsy, sensory impairments, impaired mobility, poorer communication, have been thoroughly researched in previous studies (Clements, 1992; Emerson, 1995; Murphy, 1994), yet with the exception of poor communication skills, none of these factors were shown to be predictors of daytime behaviour disturbance in the regression analyses in the current study. This offers support for the suggestion that this sample of 64 were in some way unrepresentative of a typical learning disabled population.

Attempts to improve response rates with reminder letters did little to recruit more participants for the survey. If this study was replicated it may be necessary to consider whether the length of the questionnaire deterred people from completing and returning it. Wiggs & Stores (1996) recruited their sample through schools. Response rates might be improved if the same method was used with adults and the day centres that are often attended. Receiving a letter from an unknown person may not be the most useful way of recruiting participants. If a sleep study was endorsed and supported by the day centres, families might be more willing to participate.

4.2.2 Sampling bias

Recruiting participants for the intervention was extremely problematic. All of the six participants and their carers had been selected by professionals who knew that they were committed and enthusiastic to receiving help for their particular sleep problems. This was obviously helpful in terms of compliance needed for completing the daily recordings, but again may demonstrate a bias. It is not known whether the sleep problems of the six intervention participants were particularly representative of the difficulties experienced by this population.

4.2.3 Recordings of sleep and daytime behaviour

As discussed previously, the reliability of the daily recordings of incidences of difficult behaviour remains unknown. It would improve the current study greatly if it had been possible to check the inter-rater reliability of the behaviour and sleep data. Clinical impressions and research suggest that obtaining accurate and consistent recordings from staff teams is problematic (Joyce et al., 1989). If time constraints had permitted, it would have been preferable for the researcher to spend several days throughout the 10 week period with each participant, completing daily behaviour charts as a measure of reliability. Consideration was given to asking two carers to complete sleep diaries for each participant to assess reliability (Carroll et al., 1989). However, for each participant there was only ever one adult carer around during the night, hence this was not possible.

4.2.4 Measures of stress

In this study there was not a significant change in carers' levels of stress. However, subjective reports indicate that the sleep interventions did have a positive effect on carers' stress and their ability to cope with nocturnal problems. It is possible that the Malaise Inventory was not an appropriate measure to use to assess carer stress. During recruitment it was evident to the investigator that the sleep problems in the intervention participants were a major source of stress and concern to the carers. Yet, the mean score on the inventory pre intervention (3.64) did not reach the cut off (five or six, Rutter et al., 1970)) that indicated the presence of stress. In contrast, carers of children with learning disabilities had an average score of 7.9 (Quine, 1993). The fact that the majority of respondents who completed the Malaise Inventory were paid carers may have skewed the overall results. Other measures of carer stress may have been preferable for assessing the change in stress scores following the intervention (Rose, 1993). It would be useful to separately consider the effects on stress levels of sleep problems for the different types of carers.

4.3 THEORETICAL CONTEXT

The results do not strongly support the suggestion that general sleep problems can be accepted as a setting event for challenging behaviour. A strong predictive relationship between sleep problems and behaviour disturbance has not been demonstrated. However, it is possible that the specific presence of settling problems could be a setting event for

specific behaviour disturbance, i.e. lethargy, irritability and hyperactivity. The fact that some relationship exists between some sleep disturbance and some behaviour difficulties, along with the decreasing trend in Susan's behavioural data, means that sleep continues to need consideration as a setting event from an applied behaviour analytic perspective, in particular the exploration of more specific hypotheses. Although overall the results are mixed, these specific results provide evidence that sleep as a setting event warrants further investigation before its role in applied behaviour analysis is fully accepted or rejected by those concerned with theory development (Woods & Blewitt, 1993). The need to research and consider settling problems in particular as a potential setting event is supported by the results of the survey. The only evidence that waking problems could be a contributory factor in behaviour problems is from Susan; an association between these two sets of variables requires rather more confirmatory evidence before waking problems are considered as a setting event for challenging behaviour.

Although beyond the scope of the present study, perhaps the most useful way to proceed with this investigation, in order to investigate sleep as a setting event in more detail, would be to record specific forms of behaviour difficulties more comprehensively for a shorter period of time, and actually match each day's behaviour disturbance with the previous night's sleep. This method would allow for greater sleep details to be monitored, and might be more able to identify more clearly whether subtle fluctuations in sleep impact on behaviour. Previous research has suggested that a relationship exists between these two variables in other populations, although the nature and direction of causality have not been

established. This study offers further evidence that sleep problems, particularly settling problems, could contribute to the existence of behaviour problems, and that further consideration needs to be given to sleep problems and their potential role as setting events in behaviour difficulties.

4.4 CLINICAL IMPLICATIONS

4.4.1 Prevalence rates

Whilst the prevalence figures for sleep disturbance are lower than those found in individuals with learning disabilities living in residential services, the total number of survey participants who had sleep problems that fulfilled any of the definitions used, was higher than that experienced by those within the general population (Lacks, 1987). Such results serve to confirm the findings of previous researchers that this is an important area of a person's life to enquire about clinically (Espie et al., 1995; Stores, 1992), particularly as successful interventions are being developed that can reduce the sleep problem and could improve the quality of someone's life. There was a large discrepancy between prevalence figures quoted for children with learning disabilities and the current sample (Bartlett et al., 1985; Clements et al., 1986; Quine, 1992; Wiggs & Stores, 1996). This suggests that having a sleep problem as a child does not necessarily mean that this will continue into adult life. However, the length of time for which some of the participants had had sleep problems, emphasises that professionals cannot assume that all children will 'grow out' of sleep difficulties (Clements et al., 1986). Early intervention and continued

monitoring as described by Quine (1993) would be ideal in attempting to alleviate such difficulties in childhood and preventing them from continuing into adulthood and becoming persistent.

The lack of provision of successful interventions that is evident in services for children with learning disabilities is also reflected within the current study (Hunt & Stores, 1994; Quine, 1992). Despite 21 carers reporting sleep problems in the past, only eight had been offered help. The majority of the participants who had received some help were offered medication that was ineffective and that frequently had adverse effects. It is vital that parents and carers are made aware of what interventions and treatments are available (Quine, 1992). If help was requested and medication prescribed which was ineffectual in the long term, then parents may not seek further treatments as they may be unaware of the existence of other treatments where the efficacy has been more widely demonstrated. The difficulty of parents refusing an intervention when it was offered was also mirrored in this sample (Bartlett et al., 1985). The reasons for this could be many. However, an overriding theme was that some parents felt that they would rather continue with the restrictions or consequences that the sleep difficulties imposed, e.g. sharing a bed with their son / daughter for the last 20 years, than attempt to cope with the inevitable disruption that changing this habit was likely to cause. Assessment of carers' own psychological resources would be necessary before embarking on a sleep intervention. This further supports the call for early intervention, either in childhood or as soon as the difficulties occur, so that sleep problems do not become well established and long standing. Early intervention might

also mean that the difficulties are easier to resolve and that parents are more likely to take up the offer of help. The consequences of sleep deprivation in carers might make it particularly difficult for them to successfully implement a behavioural intervention.

4.4.2 Relationship between sleep and behaviour

Despite there being evidence that supported only a highly specific relationship between settling problems and difficult behaviour (i.e. hyperactivity, lethargy and irritability), these results reflect some of the behaviour difficulties (irritability, lethargy, hyperactivity and stereotypy) that were reported by Wiggs & Stores (1996) as being co-existent with sleep problems in their sample of children with learning disabilities. This fits with the work on the effects of sleep deprivation, where people are more likely to be irritable and tired if they have had insufficient sleep. The results that show a link between sleep and hyperactivity are less easily explained. It is possible that if someone is very active throughout the day, they may be aroused physiologically, and hence calming down at bedtime may be problematic, which could explain why settling problems are evident. They may not be able to 'wind down' towards bedtime and thus are not in an optimal physical state that is conducive to sleep.

Qualitative reports from the survey suggested that carers noticed an increase daytime problem behaviour following a poor night's sleep. Whilst the empirical results do not support these anecdotal reports it could suggest that the types of behaviours that the intervention participants were monitoring were not necessarily those to which the survey

participants were referring. Specific details of the nature of the changes in behaviours that carers were referring to, could not be obtained from the survey. It could be that monitoring 'positive' aspects of an individual's behaviour such as ability to concentrate, attention, sociability etc. might yield more interesting results. Parents may have considered that their son's / daughter's behaviour was more difficult the next day following poor sleep, but this could refer to a decline in positive aspects of behaviour, rather than the occurrence of specific behaviour disturbance.

It is interesting to consider what was different about Susan and her intervention which may have resulted in the decrease in behaviour difficulties. Of all of the sleep interventions, Susan demonstrated the greatest change in the number of night wakings from the baseline period to the intervention. Therefore it is possible that the changes in sleep for the other participants, although clinically significant for the majority, were not sufficient to elicit a subsequent change in behaviour. Therefore, a greater improvement in the number of wakings or in an individual's specific sleep problem might be necessary before a significant decrease in daytime behaviour problems is evident. Susan also did not have any scores on the subscales of the ABC pre intervention above the 75th percentile, whereas all of the other participants had at least one score above this percentile. This suggests that the severity of her daytime behaviour disturbance prior to the intervention was less than that of the other participants. It could be that, as well as having to have a substantial decrease in sleep problems before behaviour improves, changes in behaviour difficulties are more likely to occur in individuals who have less severe challenging behaviour initially. Within

the theoretical context of applied behaviour analysis, it is possible that sleep problems in the other five participants may have been an initial factor in the occurrence of behaviour difficulties, but that other environmental contingencies came into operation to maintain and reinforce behaviour difficulties. Hence changes in these contingencies are required before behaviour is likely to alter. Manipulating sleep may therefore have little influence unless the secondary operant factors are also addressed.

The relationship between sleep and behaviour problems remained unclear from the interventions. It is interesting to note that there were decreases in some of the participants scores on the ABC, yet these were not statistically significant. The apparent decrease in Susan's behaviour was further supported by a reduction in her ABC scores. Similarly other participants who showed an increase in their behavioural scores according to the graphs, demonstrated a decrease in their ABC scores. This suggests that further research is required in exploring which difficult behaviours may be more or less affected from a sleep intervention, as there appears to be a discrepancy between incidence of difficult behaviours recorded and the changes in the ABC scores. The scores on the ABC show that decreases occurred in some participants irritability and lethargy scores following improvements in waking problems. It could be hypothesised that participants would be less tired and irritable if they wake fewer number of times during the night. The length of the waking is also important to consider. Further hypotheses could include that the actual amount of sleep lost rather than the number of wakings influences lethargy and irritability.

It could be that particular behavioural difficulties such as hyperactivity may influence particular sleep problems initially and not vice versa.

4.4.3 Behavioural interventions

Although it was not a specific hypothesis, this study has demonstrated that behavioural interventions can be successful in alleviating sleep problems in adults with learning disabilities. Implementing routines (Milan et al., 1981), preventing daytime sleeping (Lacks, 1987) and increasing activity levels are some straightforward and fairly simple methods used and which resulted in substantial improvements in sleep patterns.

Irrespective of whether or not it is possible to improve daytime behaviour through improving sleep, the efficacy and usefulness of behavioural interventions for sleep problems, for both carers and individuals with learning disabilities, has been demonstrated (Espie et al., 1995). When researching sleep interventions it is important to have contingency plans if change does not occur. Whilst all of the participants were aware that this was a time limited study, it could be stressful for carers if researchers withdraw their involvement. Following discussions with supervisors the two participants (Mary and Peter) who showed little change were both offered a referral to a community team.

Implementing a sleep intervention with adults with learning disabilities can appear straightforward. However, this is not always the case. Inherent in working with participants who live in residential homes is the problem of circumstantial constraints. For all of the four people who lived in such accommodation, the intervention was always

modified to an extent to fit with staffing levels, shift times etc. This can be frustrating, particularly if some of the basic principles of behaviour and sleep hygiene (Lacks, 1987) are compromised as a result. In addition, staff perception of the sleep problem plays a major role in the success of the intervention. It was argued previously that sleep problems warrant recognition as a form of challenging behaviour, yet it is clear that there are many contingencies shaping staff responses to difficult behaviour. A good example is trying to encourage participants not to sleep during the day. For John this was a major problem because when he was asleep he was quiet and staff preferred this to him being awake and active, and hence they were not motivated to prevent him from sleeping during the day. Therefore, some forms of challenging behaviour such as severe sleep disturbance may be more easily tolerated than other difficult behaviours.

One difficulty in recruiting people for the intervention was the attitude of carers to the sleep problem. There was often a discrepancy between what would be considered clinically significant, yet not seen as such by carers. Frequently carers of potential participants reported that their clients got up several times during the night for a drink or food. This was often perceived as acceptable; it was argued that clients were making a choice, and little consideration was given to the potential effects of sleep deprivation on that person. This could mean that clinicians need to undertake an educational role regarding the importance of good sleep and discussing the possible interventions (Brylewski, in press). Carers' own sleep patterns may also be an influential factor in their motivation to seek help for clients' sleep problems. Carers who themselves slept poorly,

frequently perceived this as an irritant that simply had to be accepted and lived with, and for which little could be done. Appraisal of sleep problems in this way by carers may result in people with learning disabilities not gaining access to the relevant services. Clinicians need to be pro-active by asking in clinical interviews whether sleep problems are evident (Stores, 1992c), as it is clear that carers do not often seek professional help if the sleep problem does not pose a problem to the organisation, i.e. having waking night staff (Bartlett et al., 1985).

4.5 FUTURE RESEARCH

4.5.1 Prevalence

As discussed in the Introduction, research into sleep problems with adults with learning disabilities is very sparse (Espie & Tweedie, 1991). There remains wide variation in the prevalence figures reported for this population in the few completed studies. Replication studies on this population, including both those individuals living at home and those who live in residential services, would be beneficial to the clients. This would help clarify whether the few studies completed are representative of the general picture. Additionally, there are a large number of other forms of sleep disturbance (Guilleminault, 1987; Sheldon et al., 1992), other than settling and waking problems, that have been more widely studied in other populations, that also require investigation in people with learning disabilities.

4.5.2 Relationship between sleep and behaviour

The evidence from this study regarding the relationship between sleep problems and behavioural disturbance suggests that the relationship may be highly specific. However, given that this is a new area of research, it will be necessary to explore this further before it is accepted as a general finding. The current study suggests that the presence of sleep problems in general may be a redundant variable when considering predictors of behaviour disturbance, but it is not possible to draw any definitive conclusions. However, the predictive relationship between settling and some specific behaviours (hyperactivity, lethargy and irritability), and possibly Susan's results, offer support to this being a valuable and potentially fruitful area for further research. It has also been suggested that a large decrease in sleep problems may be required before a change in behavioural disturbance would be observed. The decrease in Susan's behaviour also occurred during the second half of her eight week intervention, which suggests that a longer intervention phase may be required to monitor possible longer term influences on behaviour disturbance. It may be that there is a time lapse before the consequences of a sleep intervention affect behaviour. Thus future research might usefully intervene and monitor sleep and behaviour for longer periods than those used here. This study also only monitored the frequency of behaviour difficulties, yet severity might also be an important factor to consider. Fluctuations in the intensity or severity of behaviour problems may be an important variable when investigating the relationship between sleep and behaviour, in that improved sleep may reduce the severity of the behaviour problem, although the behaviour may not cease completely. Further research is required which examines the relationship between sleep

and daytime behaviour disturbance in more detail, with greater attention given to the size of the change of the sleep problem, the time taken for behaviour difficulties to reduce (if they do), and the type and severity of difficult behaviours that may be affected by sleep. Additionally more specific hypotheses need to be investigated between the different types of sleep problems and their relationship to particular forms of behaviour disturbance. The current study has focused on assessing the effects of sleep on behaviour, yet it is worth considering that behaviour disturbance may also affect sleep problems. Longitudinal and more intervention studies are required to further examine the relationship between these two variables.

4.5.3 Carer stress and sleep problems

The impact in terms of carer stress in caring for an adult with a learning disability who also has a sleep problem has not been widely considered within the literature. The results with regard to scores on the Malaise Inventory were only completed for a small sample of carers. Larger investigations are required to research the impact of sleep problems on carers. Clearly the carers in this sample reported lower levels of stress than those mothers of children with learning disabilities. It would be interesting to know why levels of stress were not the same as in those parents of children with learning disabilities and sleep problems, or indeed why they were not higher, particularly given that one might expect those parents of adults to have been coping with sleep problems for far longer and thus have increased stress. Have parents learnt adaptive coping strategies out of necessity? Methods of coping may warrant investigation, and how these may influence or mediate

how carers experience the stress of caring for a person with a sleep problem. Recruitment problems made it impossible in the current study, but it might be interesting to differentiate between paid carers and parents when researching carer stress and sleep problems in the future. The individual experience of stress in terms of sleep problems may be quite different for these two groups. Whilst paid carers in the intervention undoubtedly found sleep disturbance stressful and requested help to reduce this, these carers were only likely to sleep in the residence for a maximum of two nights each week. Parents or family carers, in comparison, do not receive such regular respite from sleep problems. Those paid carers in the intervention were also less likely to have had to cope with the sleep problems for the length of time than family carers had had to cope. There may be a bias in the results towards staff stress because there were more paid carers relative to parents in the intervention part of the study. These may be reasons why the overall scores on the Malaise Inventory were lower initially. At this stage it is not possible to say that one group of carers experience more stress than others, just that their respective experiences may be different and warrant further study.

4.5.4 Behavioural interventions

The purpose of this study did not include the evaluation of specific interventions for sleep problems in this population. It has however, for four out of six intervention participants, demonstrated the usefulness of many different behavioural techniques, which supports the findings from the few studies previously discussed (Hewitt, 1985; Milan et al., 1981). Research into sleep interventions for adults with learning disabilities is still lagging behind

that focusing on the general population (Espie et al., 1995). Whilst the interventions in this study utilised techniques from different populations (Espie, 1991; Lacks, 1987; Richman et al., 1985; Quine, 1993), a valuable development in the research would be to study the efficacy of the various parts of the interventions with adults with learning disabilities. It would be of benefit clinically so that well researched, clinically effective interventions could be available for use with this population (Espie et al., 1995).

4.6 CONCLUSIONS

The survey provided valuable details about the prevalence and nature of sleep problems in adults with learning disabilities who live at home with their parents, a group who have not been researched separately before. Whilst definitive conclusions cannot be drawn regarding the relationship between sleep problems and general behaviour disturbance, the study does demonstrate that there is a relationship between settling problems and hyperactivity and general behaviour problems, and perhaps also between settling problems and lethargy and irritability (although these conclusions are less certain) in this population. The intervention is, to the author's knowledge, the only systematic study that has investigated the potential effects of a sleep intervention on daytime behaviour problems in this population. The interventions demonstrated that a behavioural intervention can be successful in alleviating some waking problems in this population. However, the interventions offered less support for the hypothesis that behaviour problems would reduce following a sleep intervention, with only one participant showing a trend in this

direction. This, coupled with the results of the survey, suggest that the relationship between sleep problems and behaviour disturbance is more complex than these results suggest, and that much further research is required before any conclusive statements can be made. Carer stress was not shown to decrease after improvements in sleep had been accomplished. However, given the methodological problems considered here, it has been suggested that it would be useful for the relationship between carer stress and son's / daughter's sleep to be researched further. This study has successfully researched both a subject and a population that has not been widely considered before by sleep researchers, and it provides an original contribution to research on sleep and its relationship to daytime behaviour problems within the learning disabilities literature. In such a new area of research it is difficult to provide definitive conclusions to the hypotheses generated, particularly as there is very little previous research against which to compare the results. However, the study demonstrates the clinical benefits of sleep research and interventions with adults with learning disabilities. The results suggest many avenues for further research, and will hopefully stimulate further discussion and research into this important topic.

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APPENDIX 1

SLEEP QUESTIONNAIRE

Thank you for taking the time to fill in this questionnaire

Any information you give will be confidential

Please answer all of the questions

**If you have any questions or concerns about this questionnaire, please
telephone:**

GEMMA GRAY *****

PART ONE

We would be grateful for the following information about your son / daughter

Name _____

Address _____

Telephone
number _____

Daytime occupation (e.g. day centre) _____

Date of birth _____

Sex (M / F)

Date of completing the questionnaire _____

Questionnaire completed by _____ (your name)

Relationship to son / daughter (e.g. mother, father) _____

Who else lives at the home address?

Details of brothers and sisters (sex, date of birth etc.)

Occupation of father

Occupation of mother

Name any illness or physical disorder that your son / daughter has at present or has had within the last month.

Details of any treatment / medication which your son / daughter has currently or within the last month.

Does your son / daughter have any significant allergies or infections involving ears, nose or throat?

YES NO

Does he or she suffer with a blocked nose?

() All the time
() Occasionally
() Never

Does your son / daughter have epilepsy?

YES NO

Have you been given a diagnosis for the cause of your son / daughters learning disability?

Diagnosis () (please state)

Unknown cause ()

Does your son / daughter have any other medical conditions?
(please state)

YES NO

Does your son / daughter have problems with their eyesight?

YES NO

Does your son / daughter have hearing problems?

YES NO

Does your son / daughter have physical disabilities?

YES NO

How much speech does your son / daughter have?

() None
() Few single words
() Few phrases
() Full sentences

What is their height?

What is their weight?

Have they gained / lost weight within the last 6 months?

() GAINED () LOST

(please state how much)

How many cups of tea / coffee do they drink between

7 - 12 am _____?

12 - 6 pm _____?

6pm - midnight _____?

How often do they drink alcohol?

Daily Weekly Monthly Occasionally Never

PART TWO

In this section we would like to know about your son's / daughter's present sleeping habits, and to see whether there are any parts of their sleeping habits which are a problem for you or them. Please base your answers on your son's / daughter's sleep during the LAST MONTH ONLY.

1. Does your son / daughter usually sleep on their own in bed? YES NO
2. If NO who do they usually sleep with ?
 - () Brother
 - () Sister
 - () Parents
 - () Other
3. How many other people sleep in the same room?
4. What time do they start getting ready for bed?
Please describe their bedtime routine
5. What time does your son / daughter usually go to bed?
6. What time does your son / daughter usually go to sleep?
7. Does he / she have problems settling to sleep?
 - () No, settles to sleep immediately
 - () Yes, but entertains self until sleep
 - () Yes, needs parents to settle them
 - () yes, big problems, cries, comes downstairs etc.
8. If YES how often are there problems with settling?
 - () Less than once a month
 - () About once a month
 - () 2 - 4 times a month
 - () 1 - 2 times a week
 - () 3 times or more a week
 - () Daily

9. If YES how long does it usually take to settle him / her?

- ☐ Few minutes
- ☐ Up to half an hour
- ☐ Up to 1 hour
- ☐ Up to 2 hours
- ☐ 3 hours or more

10. If YES please describe the problem and exactly what happens.

11. If your son / daughter won't settle what do you do about it?

12. In what way does the problem affect you?

13. How long does it take them to fall asleep?

14. Is your son / daughter a light sleeper? YES NO

15. Do they usually wake in the night? YES NO

16. If YES, how often do they wake in the night? ☐ Less than once a month
☐ About once a month
☐ 2 - 4 times a month
☐ 1 - 2 times a week
☐ 3 times or more a week
☐ Daily

17. If YES how many times a night do they wake? ☐ Once
☐ Once or twice
☐ About 3 times
☐ 4 or more times

18. How long does it usually take to re-settle him / her ?
☐ A few minutes
☐ Up to half an hour
☐ Up to 1 hour
☐ Up to 2 hours
☐ 3 hours or more

19. What does your son / daughter do before going back to sleep? (e.g. go to the toilet, crying etc.)

20. Does your son / daughter come into your bed or do you sleep in their bed if they are upset?
YES NO
21. If YES how often?
() Once per week or less
() Twice per week or more
() Other (please state)
22. If he / she does come into your bed, how long do they stay there?
() For all or most of the night
() For a couple of hours only
() Other (please state)
23. Once asleep does he / she sleep soundly? YES NO
24. What time does your son / daughter wake in the morning?
25. What do they do when they wake up? (e.g. cries, wakes you etc.)
26. What time does he / she get up?
27. Does your son / daughter have to be woken in the morning? YES NO
28. Does your son / daughter wake in the morning before 5 am and stay awake? If YES how often?
() Never
() Less than once a month
() About once a month
() 2 - 4 times a month
() Several times a week
() Daily
29. Does he / she usually wake up well rested? YES NO
30. Does he / she wake up in a bad mood? YES NO
31. Does he / she wake up feeling tired? YES NO
32. (a) If YES what part of the day are they most tired?
() Morning
() Afternoon
() Evening
() No difference - all day
- (b) Does your son / daughter sleep during the day? YES NO
Please state at what time and for how long.

33. If your son / daughter has a poor night's sleep is his / her behaviour difficult the next day?
YES NO
34. If YES are there particular times of the day that it is most difficult?
35. If YES when is it difficult?
() Morning
() Afternoon
() Evening
() All the time
36. Have you ever had any advice or treatment for their sleep? YES NO
37. If YES please describe this.
38. If YES was the advice / treatment helpful? YES NO
39. In what ways was the advice or treatment helpful?
40. In what way was the advice / treatment not helpful?
41. In your opinion does your son / daughter have a sleep problem? YES NO
42. If YES what would you say this problem was? (e.g. settling problem, night waking, both etc.)
43. If YES how long have they had this sleep problem?
44. If YES please state who attends to them at these times?
45. If YES does any else suffer as a result of this sleep problem. (please state)

46. If YES would you like to receive advice / treatment for the current sleep problems?

YES

NO

47. If your son / daughter has a sleep problem, but you would not like NO advice or treatment, is there a reason why you want no help?

48. Has your son / daughter had a sleep problem in the past?

YES

NO

49. If YES please describe it.

50. Do you feel that you get enough sleep yourself?

YES

NO

51. If NO why do you not get enough sleep?

52. Do other members of the family suffer from loss of sleep?

YES

NO

53. If YES please give details of who suffers and why and how their sleep is disturbed.

54. Is there any other information about your son / daughter that you think is important and we have not mentioned? Please give details below.

PART THREE

During the past month has your son/daughter shown any of the following behaviours. Please tick the box which describes how often each behaviour occurs.

	DESCRIPTION	Never	Less than once a month	About once a month	Two to four times a month	Many times a week	Daily
1	Talks in sleep						
2	Walks in sleep						
3	Grinds teeth in sleep						
4	Bangs head in sleep						
5	Rolls from side to side rhythmically in sleep or while going off to sleep						
6	Moves around a lot in bed during sleep (restless sleep)						
7	Bites tongue during sleep						
8	Snores loudly during sleep						
9	Gags, chokes, or snorts loudly during sleep						
10	Seems to repeatedly stop breathing for periods of time lasting up to 30 secs during sleep						
11	Makes quick movements of the arms and legs (e.g. kicking and flailing) during sleep						
12	Wets the bed during sleep						
13	Insists on sleeping with somebody else						
14	Doesn't want to go to bed because he / she is afraid						
15	Expresses fear that if he / she goes to sleep they might die						
16	Afraid of the dark						
17	Needs security object (e.g. teddy bear) before he / she goes to sleep						
18	Insists on bed time rituals (e.g. bed time story) before sleep						
19	Needs sleeping medication						
20	Wakes in night complaining of nightmares or frightening dreams						
21	Wakes during the night screaming in terror. Anxiety may be so bad that sweating, gasping or trembling may happen. He / she is not aware of their surroundings and may not remember it the next day						
22	During the day, muscles become so weak that he / she has to lie down before falling (usually after laughing or crying)						
23	During the day, has urges to go to sleep and can't stop himself / herself						
24	Seems drowsy during the day, but can stop himself / herself from sleeping						
25	During the day, appears more active than other people						
26	Upon waking, feels paralysed even though he / she is aware of the surroundings						

PART FOUR

These are questions about your son /daughters daytime behaviour. Please think of their behaviour over the last month. For each behaviour described please circle the appropriate number.

0 = not a problem at all

1 = this behaviour is a slight problem

2 = this behaviour is quite a serious problem

3 = this behaviour is a serious problem

Do not spend too much time on each item, your first reaction is usually the right one.

1	Excessively active at home, work or elsewhere	0	1	2	3
2	Injures self on purpose	0	1	2	3
3	Listless, sluggish, inactive	0	1	2	3
4	Aggressive to other children or adults (verbally or physically)	0	1	2	3
5	Seeks isolation from others	0	1	2	3
6	Meaningless, recurring body movements	0	1	2	3
7	Boisterous (inappropriately noisy and rough)	0	1	2	3
8	Screams inappropriately	0	1	2	3
9	Talks excessively	0	1	2	3
10	Temper tantrums / outbursts	0	1	2	3
11	Stereotyped behaviour: abnormal, repetitive movements	0	1	2	3
12	Preoccupied: stares into space	0	1	2	3
13	Impulsive (acts without thinking)	0	1	2	3
14	Irritable and whiny	0	1	2	3
15	Restless, unable to sit still	0	1	2	3
16	Withdrawn; prefers solitary activities	0	1	2	3
17	Odd, bizarre in behaviour	0	1	2	3
18	Disobedient; difficult to control	0	1	2	3
19	Yells at inappropriate times	0	1	2	3
20	Fixed facial expression; lacks emotional responsiveness	0	1	2	3
21	Disturbs others	0	1	2	3
22	Repetitive speech	0	1	2	3
23	Does nothing but sit and watch others	0	1	2	3
24	Uncooperative	0	1	2	3
25	Depressed mood	0	1	2	3
26	Resists any form of physical contact	0	1	2	3
27	Moves or rolls head back and forth repetitively	0	1	2	3
28	Does not pay attention to instructions	0	1	2	3
29	Demands must be met immediately	0	1	2	3
30	Isolates himself / herself from other children or adults	0	1	2	3
31	Disrupts group activities	0	1	2	3
32	Sits or stands in one position for a long time	0	1	2	3
33	Talks to self loudly	0	1	2	3
34	Cries over minor annoyances and hurts	0	1	2	3
35	Repetitive hand, body, or head movements	0	1	2	3
36	Mood changes quickly	0	1	2	3
37	Unresponsive to structured activities (does not react)	0	1	2	3
38	Does not stay in seat (e.g., during activity sessions, meals etc.)	0	1	2	3

39	Will not sit still for any length of time	0	1	2	3
40	Is difficult to reach, contact, or get through to	0	1	2	3
41	Cries and screams inappropriately	0	1	2	3
42	Prefers to be alone	0	1	2	3
43	Does not try to communicate by words or gestures	0	1	2	3
44	Easily distractible	0	1	2	3
45	Waves or shakes the extremities repeatedly	0	1	2	3
46	Repeats a word or phrase over and over	0	1	2	3
47	Stamps feet or bangs objects or slams doors	0	1	2	3
48	Constantly runs or jumps around the room	0	1	2	3
49	Rocks body back and forth repeatedly	0	1	2	3
50	Deliberately hurts himself / herself	0	1	2	3
51	Pays no attention when spoken to	0	1	2	3
52	Does physical violence to self	0	1	2	3
53	Inactive, never moves spontaneously	0	1	2	3
54	Tends to be excessively active	0	1	2	3
55	Responds negatively to affection	0	1	2	3
56	Deliberately ignores directions	0	1	2	3
57	Has temper outbursts / tantrums when he / she does not get own way	0	1	2	3
58	Shows few social reactions to others	0	1	2	3

**THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS
QUESTIONNAIRE**

**PLEASE RETURN IT IN THE STAMPED ADDRESSED ENVELOPE PROVIDED
TO:**

GEMMA GRAY

APPENDIX 2

Dear Ms Gray

**RE: OPREC APPLICATION NO: 96-40
AN INVESTIGATION INTO SLEEP PROBLEMS AND BEHAVIOURAL
DIFFICULTIES IN ADULTS WITH LEARNING DISABILITIES WHO LIVE AT
HOME, AND THE IMPACT OF THIS UPON THEIR CARERS.**

Thank you for your letter of 6 January 1997. Your study now has full ethics approval.

With kind regards.

Yours sincerely

Chairman, \
 /, Consultant Psychiatrist
 ' Psychiatric Research Ethics Committee

cc: Mr Richard Adams, Consultant Clinical Psychologist, :

Dear Ms Gray,

RE: OPREC NO. 96/40 - An investigation into sleep problems and behavioural difficulties in adults with learning disabilities who live at home, and the impact of this upon their carers.

Thank you for your letter of the 21st January 1997. In view of the fact that you will continue with the originally approved consent procedure, I can give Chairman's approval to your using the alternative means of recruitment as outlined in your letter.

Best wishes.

Yours sincerely,

Consultant Psychiatrist
Chairman
Psychiatric Research Ethics Committee

APPENDIX 3

HEALTH QUESTIONNAIRE

This questionnaire is about particular problems you might have had with YOUR health in the last few weeks. Just ring 'yes' or 'no' for each answer.

Do you often have back ache?	YES	NO
Do you feel tired most of the time?	YES	NO
Do you often feel miserable or depressed?	YES	NO
Do you often have bad headaches?	YES	NO
Do you often get worried about things?	YES	NO
Do you usually have great difficulty in falling asleep or staying asleep?	YES	NO
Do you usually wake unnecessarily early in the morning?	YES	NO
Do you wear yourself out worrying about your health?	YES	NO
Do you often get into a violent rage?	YES	NO
Do people often annoy and irritate you?	YES	NO
Have you at times had a twitching of the face, head, or shoulders?	YES	NO
Do you often suddenly become scared for no good reason?	YES	NO
Are you scared to be alone when there are no friends near you?	YES	NO
Are you easily upset or irritated?	YES	NO
Are you frightened of going out alone or of meeting people?	YES	NO
Are you constantly keyed up and jittery?	YES	NO
Do you suffer from indigestion?	YES	NO
Do you often suffer from an upset stomach?	YES	NO
Is your appetite poor?	YES	NO
Does every little thing get on your nerves and wear you out?	YES	NO
Does your heart often race like mad?	YES	NO
Do you often have bad pains in your eyes?	YES	NO
Are you troubled with rheumatism or fibrositis?	YES	NO
Have you ever had a nervous break down?	YES	NO

APPENDIX 4

SLEEP DIARY FOR _____

Date		
Time woke / woken up		
Time got up		
Time and length of naps during the day		
Time upstairs		
Time to bed		
Time to sleep		
Please describe what happened in the time between bed and sleep		
TIMES AND LENGTH OF ANY NIGHT WAKINGS. What happened, at what time, what did you do, how did you re-settle him or her, how long did it take to settle etc.		

APPENDIX 5

Here are a list of behaviours that Susan shows. Every time one of them occurs, please put a tick(s) in the relevant box. It is likely that there will be more than one tick in some boxes.

[illegible]

PETER'S BEHAVIOUR CHART

Here are a list of behaviours that Peter shows. Every time one of them occurs, please put a tick(s) in the relevant box. It is likely that there will be more than one tick in some boxes. *Please note if Peter sleeps during the day, and how long for.*

	DAY		
	AM	12-6	6-BED
Hitting staff			
Picking up object as if to throw it			
Lifting skirts up			
Rubbing himself against other people			
Rubbing himself against furniture / objects			
Shouting			
Running up and down the corridor			
Banging doors			
Hitting glass with his hand			
Hitting other clients			
<i>Sleep / naps taken during the day</i>			

Gemma Gray

If you have any queries, please do not hesitate to contact me on

APPENDIX 6

John's guidelines

1. It would be helpful for John to go for a walk or have some exercise in the early evening.
2. During handover period, at 9.15 p.m. offer John a bath, using both the day and night staff.
3. Give John his medication, help him put on his pyjamas. Please do not put them on him before he gets ready for bed.
4. Settle John into bed, saying 'goodnight'.
5. When you settle John into bed please do not put his disco lights on.
6. If John does get up in the night, encourage him to return to his room with minimal fuss and talking.
7. As John gets up several times each night it is important that No. 6 is repeated as often as necessary.
8. If John refuses to return to his room, it is important that the environment is not rewarding for him. Please turn the television and radio off and use minimal talking and fuss.
9. John should be encouraged not to sleep during the day.
10. During the night please try and keep stimulation levels to a minimum.
11. John should not be given food during the night - he may learn to expect this. Do offer him drinks if necessary.
12. If John falls asleep in the lounge just before bedtime or in the early evening, encourage him to go to bed properly rather than let him sleep on the sofa.

Jane's Guidelines

1. When Jane starts to look sleepy, ask her if she would like to go to bed.
2. Offer Jane a bath, with bubbles in it - this seems to relax her.
3. Ensure that she has been to the toilet before she gets into bed.
4. Encourage Jane to get into bed and help her get settled. Say "goodnight Jane, sleep well"
5. Leave the room and switch off the light.
6. Encourage Jane not to sleep during the day

Jane's Chart

1. Before settling Jane into bed, remind her of her sleep chart. Show the chart to her (stuck on the inside of her wardrobe) and show her the stickers that she has already achieved.
2. Remind Jane that she needs to be quiet tonight. Put your finger to your mouth to indicate sshh.
3. If Jane is quiet until 4.00 am please give her a sticker in the morning. Once Jane has achieved remaining quiet until 4.00 am, we will gradually lengthen the time so that she is quieter for longer.
4. It is important to give Jane lots of praise - "well done, that's great Jane. You tried really hard and were quiet when you went to bed"

5. If Jane does shout before 4.00 am, do not do anything or draw attention to her chart
6. Do not remove stickers from her chart if she has a disrupted night.
7. The aim is to positively encourage appropriate night-time behaviour.